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ABSTRACT

By the year 2000 between 72,000 and 125,000 children and teenagers in the United States will have lost their mothers to the Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS). An additional 60,000 young adults (18 and older) will also have lost their mothers. The hardest hit cities are New York City (New York), Newark (New Jersey), Miami (Florida), San Juan (Puerto Rico), Los Angeles (California), and Washington, DC. These major urban areas are expected to account for nearly 60 percent of the projected number of orphans. This report offers recommendations for programs formulated at a conference of The Orphan Project to meet the needs of orphaned youngsters, their families, and their new guardians. Recommendations are discussed in the areas of (1) services; (2) training and professional development; (3) public policies; (4) legal standards; (5) further research needs; and (6) issues for future policy analysis. Areas where conference participants were not able to agree, particularly with regard to HIV disclosure policies, funding, and child care decisions, are reviewed. An appendix lists conference participants from the Orphans Project Meeting, June 3-4, 1993. (SLD)

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ORPHANS of the HIV EPIDEMIC

Unmet Needs in Six U.S. Cities

Carol Levine

Gary L. Stein

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ORPHANS *of the* HIV EPIDEMIC

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THE ORPHAN PROJECT

NEW YORK CITY

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EXECUTIVE SUMMARY

① Orphans of the HIV Epidemic: A National Problem

By the year 2000 between 72,000 and 125,000 children and teenagers in the United States will have lost their mothers to HIV/AIDS. An additional 60,000 young adults (18 and older) also will have lost their mothers.

The hardest-hit cities are New York City, Newark, Miami, San Juan, Los Angeles, and Washington, D.C. Medium-range estimates for the number of children and adolescents who will be motherless because of AIDS by the year 2000 are:

New York City:	30,000	(15,000 children,	15,000 adolescents)
Newark:	7,200	(4,700 children,	2,500 adolescents)
Miami:	4,900	(3,200 children,	1,700 adolescents)
San Juan:	4,200	(2,900 children,	1,300 adolescents)
Los Angeles:	1,900	(1,200 children,	700 adolescents)
Washington, D.C.:	1,400	(900 children,	500 adolescents)

These major urban centers account for approximately 60 percent of the total number of orphans; 40 percent will be in other cities, suburban areas, and rural areas.

The problem is national in scope and requires national leadership. Although solutions will vary depending on local needs, there must be a coordinated and comprehensive response from the federal and state governments in partnership with relevant national and local groups.

② Unmet Needs of HIV-Affected Youth

Most orphaned youngsters are not HIV-infected but are at high risk for a range of behavioral and developmental problems, as well as for engaging in high-risk behaviors associated with HIV transmission.

Although a broad range of services is required, including health care, the most urgent needs are for mental health services, including bereavement counseling; transitional services for the reorganized family to help overcome the loss of AIDS-related benefits following the parent's death; legal services; housing supports; and appropriate evaluations and referrals by juvenile justice and school staff to community-based services.

Although there are many innovative and successful service models, to date the needs of well children orphaned by AIDS have not been met either by AIDS-specific services focused on their parents or siblings or by general child welfare and youth organizations.

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3 Recommendations

Federal, state, and local child welfare and AIDS service agencies, in collaboration with private agencies and community-based organizations and family members, should develop programs to meet the needs of orphaned youngsters, their families, and new guardians. The programs should reflect both the universal needs of children and families and specific local conditions.

A. Services

- Mental health services, including bereavement counseling, should be developed and targeted to different ages, cultural backgrounds, and periods of intervention.
- Transitional services for youth and their new guardians should be created to provide an orderly move from AIDS-specific entitlements and services to more general programs.
- HIV-affected youth involved in family court proceedings require proper evaluation and referral to appropriate community services, especially mental health services.
- Schools should be an important locus of child- and youth-centered services, prevention programs, and staff training. Community and neighborhood programs targeting out-of-school youth are also essential, since many of the most vulnerable youth do not attend school regularly.
- Housing supports, including rent subsidies, should be created to keep existing families together and to promote the development of new, stable family arrangements.
- Agencies should simplify regulations and requirements and produce easily understandable consumer handbooks.

B. Training and Professional Development

- National, regional, and local conferences and meetings should continue the dialogue on the needs of families and youth affected by HIV.
- Public and private providers, universities, and professional programs should ensure the availability of qualified and motivated staff by developing curricula, internships, and other training programs to address the needs of families affected by HIV.
- Public and private providers should develop innovative programs to train family members (birth, foster, kinship, and adoptive) on effective negotiation strategies to obtain needed services.
- Public and private providers and universities should collaborate with legislators and agency regulators to enhance the traditionally low salaries of professionals serving in underserved, poor communities, and to create other incentives for recruitment and retention.

C. Public Policies

- Foster care agencies should develop flexible and supportive foster care programs for voluntary placement of children during the parent's illness, return of the children during periods of good health, and continuing foster care, ideally leading to adoption, following the parent's death; these programs should promote continuity and shared responsibilities.

- Agency regulations should be revised to permit subsidies for low-income guardians; new authorizing legislation may be needed at federal and state levels.

- Children of undocumented persons should be eligible for appropriate services.

D. Legal Standards

- New state laws (and federal laws that encourage or require states to enact such legislation) should be created to enable parents to appoint standby guardians, thereby permitting them to have continued custody and control of their children for as long as their health permits, while facilitating transition to guardianship after they die. Such legislation should not jeopardize the guardian's eligibility for foster care subsidies.

- Public and private funds are needed to expand legal service programs targeted to women and families with HIV.

- State legislatures and social service agencies should comply with the Interstate Compact on the Placement of Children, clarify the responsibilities of sending and receiving states where necessary, and promote interstate communication among judges and child welfare caseworkers.

- Judges should be trained on the legal, medical, and psychosocial needs of families affected by HIV and should have adequate resources to hear HIV-related family cases.

- Legislators should clarify the legal status of adolescents, particularly their ability to consent to medical care and to participate in other major life decisions.

E. Further Research Needs

In order to use limited resources wisely and provide optimal services, the following research should be conducted:

- Further refinements of epidemiological data to take into account the lack of data on fathers, changes in the epidemic, treatment advances, and the aging of children

- Follow-up and analysis of family cases to determine who cares for orphaned children and adolescents, the numbers and ages of children in foster care, the legal status of new guardianship arrangements, the extent to which siblings are separated, and long-term outcomes
- Research on the impact of the growing number of orphans in smaller cities and rural areas, which may lack the range of services found in larger cities
- Anthropologic/ethnographic studies to describe the cultural milieu of families and how these factors affect custody arrangements
- Studies examining the impact on adolescents of caring for younger siblings without parental supervision
- Studies of bereavement in children of different cultural backgrounds
- Data on how and where families access services
- Evaluation of strategies to promote public support for programs that assist families affected by HIV
- Psychosocial research on strategies to document family histories
- Studies of different patterns of disclosure of HIV status within the family

F. Issues for Future Policy Analysis

In order to develop more effective governmental policies and publicly-funded programs for orphaned children and youth, the following policy areas require additional analysis:

- The applicability of Ryan White Comprehensive AIDS Resources Emergency (CARE) Act funding to well family members and an examination of possible statutory amendments in proposals to reauthorize this legislation
- The impact of the Interstate Compact on the Placement of Children and of the failure to enact compact procedures in Puerto Rico
- The relationship between custody planning and eligibility for benefits and entitlements
- Standards, subsidies, and services for kinship caregivers
- The relationship in youths between HIV-related losses and encounters with the juvenile justice system

G. Areas Where Conflicting Views Surfaced

The following issues generated considerable discussion and differing opinions at the June 1993 meeting sponsored by The Orphan Project:

- Should disclosure of HIV status within the family, and especially to children, be strongly encouraged, supported but not encouraged, or left solely to families' discretion?
- How can the competing claims of birth and foster parents to make child care decisions be reconciled?
- Should the needs of children orphaned by HIV/AIDS be addressed through categorical programs and funding or through reform of existing systems that affect families, such as child welfare, education, the judiciary, and health care?

INTRODUCTION

Defining the Problem

"Each poem [about black mothers and daughters] makes me know again as if for the first time that the most moving song created during my people's turmoil of slavery was and remains, 'Sometimes I feel like a motherless child.'"

— Maya Angelou*

At the close of the twentieth century in the United States, the lament has become reality. By the year 2000, as many as 125,000 children and adolescents will be motherless because of a single disease. Their mothers, and in many cases their fathers too, will have died of AIDS. And the end of the epidemic is nowhere in sight.

The vast majority of these youngsters are not HIV-infected but are at high risk for a range of behavioral and developmental problems. At least 80 percent of them come from poor communities of color, which have already been devastated by society's neglect. The teenagers are at risk for engaging in sexual and drug-using behaviors associated with HIV transmission.

Along with their unique problems, the orphans of the HIV† epidemic share some characteristics of children whose parents have died of other causes; all such children grieve the loss and need care. They also share some characteristics of children living in the same communities whose families are not directly affected by HIV; all such children need better education, improved living conditions, and greater economic opportunities, as well as freedom from violence, discrimination, and the ravages of drugs and alcohol. The orphans of the HIV epidemic are of particular concern because of their cumulative vulnerabilities. Programs addressed to meet their needs can be models for those serving all children in difficult circumstances. Just as the AIDS epidemic highlighted the shortcomings of our health care and social services delivery systems, the problems of children and youth orphaned by AIDS accentuate the deficiencies of child welfare and anti-poverty programs.

* Foreword to *Double Stitch*, edited by Patricia Bell-Scott et al., Beacon Press, 1991.

† Unless otherwise stated, use of the term "HIV" refers to the spectrum of HIV disease, including HIV infection and AIDS.

The phenomenon of a very large group of orphans whose parents have died of a single disease appears to be unprecedented in American history. AIDS, a disease unknown before 1981, has become the leading cause of death for American men aged 25 to 44 and the fourth-leading cause of death among women in that age group.[1] In 1991, AIDS was the leading killer of black men ages 25 to 44 and the third leading killer among black women in that age group. Within that same age range, it was the second leading cause of death among white men and sixth among white women.[2] The great flu pandemic of 1918, which swept through the country but then disappeared, offers only a partial analogy. So too does tuberculosis, which also struck young people in the late nineteenth and early twentieth century, but is a centuries-old disease.

When orphanages proliferated in this country, from the 1880s to the 1940s, hundreds of institutions were filled with tens of thousands of children. While some of these youngsters had lost a father or mother or both parents, many (perhaps most) were not orphans. Some were institutionalized because their parents were so poor that they could not afford to keep them. Some had been abandoned. Some had been removed from the home because of abuse or neglect. Moreover, at least 200,000 infants, children, and teenagers were "placed out," that is, sent westward from eastern cities to rural areas where they could be absorbed by charitable or labor-needy farm families. These youngsters too were mostly not orphans but destitute residents of city slums and streets.[3]

The current situation, then, presents a novel challenge. What kinds of public and private responses will best meet the needs of a large and growing number of youngsters whose mothers, fathers, and often other family members are living with HIV or have died of the disease? Earlier solutions — institutionalization or placing out — are no longer politically, psychologically, or economically viable. The foster care system, which developed in response to the inadequacies of these earlier solutions, is itself overwhelmed. Although there are many innovative and successful service models, the majority of the well children's needs have not been met either by AIDS-specific services focused on their ailing parents or siblings or by general child welfare and youth organizations. What, then, can and should be done with today's knowledge and resources to offer well children and their families the best possible opportunities?

To begin to answer these complex questions, The Orphan Project convened a two-day meeting of specialists from New York City; Newark, New Jersey; Washington, D.C.; San Juan, Puerto Rico; Miami, Florida; and Los Angeles, California, as well as representatives of national

private and public child welfare agencies, and a group of family members from New York City (see Appendix for list of participants).* The meeting was supported by grants from the American Foundation for AIDS Research and the Prudential Foundation. The production of this report was made possible by a contribution from Johnson & Johnson Family of Companies and additional support from the Prudential Foundation.

The Orphan Project's June 1993 meeting was the first national forum on the concerns of children and youth orphaned by AIDS. However, as participants made clear, continued dialogue is needed on the range of issues discussed in this report. Conferences on national, regional, and local levels should be convened to promote a comprehensive agenda on orphaned children.

The six cities were chosen because they have the largest numbers of reported AIDS cases among women in the nation, and therefore will have the largest numbers of surviving children. The problem, however, is not confined to these cities. Wherever there are women with AIDS — in rural areas, suburban regions, and small cities — there will be orphaned children. This is a national problem; there must be national leadership. The solutions will vary depending on local conditions, but there must be a coordinated and comprehensive response from the federal government and from national groups, as well as from state and local governments and community-based organizations. The National Commission on AIDS called for such a response when it recommended that "Federal and state government should . . . support programs designed to assist family members in caring for children whose lives have been affected by HIV/AIDS."[4]

This report does not address the specific needs of HIV-infected children; many other excellent reports accomplish that task.[5] However, insofar as the needs of these children are the same as those of their healthy siblings — for example, assistance in grieving the death of a parent — they are discussed here. The specific recommendations contained in this report are based on the following general principles relating to children, families, communities, and AIDS policy.

Policies affecting youngsters should recognize that each child or adolescent is a unique individual with specific needs and potential for growth and development. Moreover, the family should be the

* The broad consensus that emerged at the meeting is reflected in the structure of this report and its principal recommendations. The authors of the report, however, used sources beyond the meeting to develop the report and are solely responsible for the presentation of the issues and the recommendations. Three subjects that generated considerable disagreement at the meeting are discussed in Chapter 4.

initial center for nurturing, care, and services. Recognizing the realities of contemporary life, families must be broadly defined to include relationships that offer strength and stability for children, even though these relationships may not be biological or formalized by law. Other relationships are appropriate when there is no biological or legal family or when these relationships are too fragile or destructive to the child to be supported. Affected families should be equal partners with providers and policy makers in planning and service delivery. Because many of the affected youth and families are concentrated in particular communities, services and policies should respect and reflect community cultural values.

Services should be comprehensive and ensure continuity of care. For example, identifying depression and grief and making referrals to preventive services can forestall serious problems later on. Schools can serve as an important locus of child- and youth-centered services, prevention programs, and staff training. However, youths not attending school must also be reached.

In the broad context of AIDS programs and policies, public education must be expanded to reduce the societal stigma surrounding HIV and to help prevent further transmission. Confidentiality of HIV-related information must be maintained; discrimination based on HIV status must be prevented, where possible, and penalized when it occurs. Finally, biomedical research must be accelerated in order to improve patients' quality of life, to prolong survival, and ultimately to reduce the numbers of children orphaned by HIV.

References

1. "AIDS is Top Killer Among Young Men," *The New York Times*, October 31, 1993.

2. "Americans' Life Expectancy Rises to 75.5 Years," *The New York Times*, September 1, 1993.

3. Marilyn Irvin Holt, *The Orphan Trains: Placing Out in America* (Lincoln: University of Nebraska Press, 1992).

4. National Commission on AIDS, *The Challenge of HIV/AIDS in Communities of Color* (Washington, D.C., 1992), 7.

5. See, for example, Gary Anderson, ed., *Courage to Care: Responding to the Crisis of Children with AIDS* (Washington D.C.: Child Welfare League of America, 1990); Philip A. Pizzo and Catherine M. Wilfert, eds., *Pediatric AIDS: The Challenge of HIV Infection in Infants, Children, and Adolescents* (Baltimore: Williams & Wilkins, 1991); U.S. Public Health Service, *Family-Centered Comprehensive Care for Children with HIV Infection* (Washington D.C.: August 1991); and Allen C. Crocker, Herbert J. Cohen, and Theodore A. Kastner, *HIV Infection and Developmental Disabilities: A Resource for Service Providers* (Baltimore: Paul H. Brookes Publishing Co., 1992).

PROFILE **Linda S.**

"I'm never giving up on myself"

LINDA S.

In the three years since she was diagnosed as HIV-positive, Linda S. has coped with the loss of her eight-year-old son to AIDS and her own grave illness. Still, she fights on with the determination of a survivor. "I'm never giving up on myself," she says insistently. "I'm not going to lay down and let this thing beat me. That's my attitude and I try to inflict it on everyone else."

She credits her strength to the help she gets from people who care and emphasizes that the long road of HIV disease cannot be travelled alone. "Our mental aspects are just as important as our physical aspects," says Linda S., who runs a support group. "We need counseling, we need support groups, we need psychologists. A major concern for many of us is that our insurance won't pay for a lot of it."

Linda's group includes mothers, fathers, and grandparents. "It is open to anyone who is affected or infected," she says. "We talk about our issues, we share our experiences, and we exchange information. Sometimes, we give each other more information than we are given at the hospital."

One of the topics that arises frequently is the caretaking arrangements that must be made for children who will be left behind. Although Linda has made plans for her 16-year-old son, she understands people who cannot face such decisions. "They are scared, they ask me, 'Linda, how can you sign that paper?' My answer is, 'Look, honey, the last thing I want to be worried about on my deathbed is where my child is going.'" Still, she respects their reticence. "People are afraid of saying they are giving up. It's scary. We need a positive attitude and we need people who will help us see that making these decisions has nothing to do with giving up."

As an AIDS survivor, Linda S. has encountered many of the holes in the social service system. "It is very difficult for a lot of us who have older children," she says. "I'd like to be able to say, 'Look, I have to go into the hospital for two months, can you put my child in foster care?' But I can't do that. If I do, I'm not going to get my child back. The system wants to keep him."

Equally disturbing has been her inability to get life insurance. "I don't know who is in charge, but the insurance companies have all this power to say 'yes' or 'no.' We don't need $50,000 and a fancy coach and singing down the halls but let us have plans that will provide us with $2,000 or $3,000, just something that makes us feel comfortable. For a lot of us, that is a major concern."

Despite the obstacles and the moments she describes as "really rough," Linda S. feels at peace. "The important thing is to stay involved. I tell people not to sit back and dwell on their problems. If they feel like they are doing something, it makes them feel a whole lot better."

CHAPTER ONE

Estimating the Number of Children and Adolescents Orphaned by HIV

From the first five cases of a mysterious syndrome reported to the U.S. Centers for Disease Control and Prevention (CDC) in 1981 to the millions of cases of HIV infection estimated by the World Health Organization (WHO) today, epidemiologists have tried to quantify almost all aspects of the rising tide of the AIDS epidemic. Even though the epidemic has hit hard at women and men in their prime reproductive years, only recently has a basic question been raised: How many children and adolescents will survive the HIV-related death of a parent?

People living and working in the hardest-hit communities have known many families with surviving children, but there has been no epidemiologic model to estimate their actual number. As one of its first tasks, The Orphan Project developed such a model for New York City and the United States and then applied this model to the five other cities represented at the meeting.*

The various categories of children and adolescents who are infected with or affected by HIV can be represented schematically in the form of an iceberg (Figure 1).

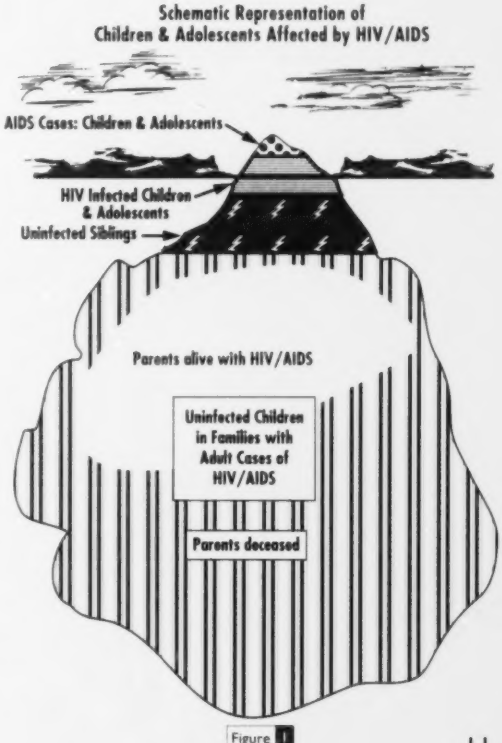
Schematic Representation of
Children & Adolescents Affected by HIV/AIDS
AIDS Cases: Children & Adolescents
HIV Infected Children & Adolescents
Uninfected Siblings
Parents alive with HIV/AIDS
Uninfected Children in Families with Adult Cases of HIV/AIDS
Parents deceased

Figure 1

* The following sections are based on the work of David Michaels, Ph.D., M.P.H., associate professor of epidemiology in the Department of Community Health and Social Medicine at the City University of New York Medical School/Sophie Davis School of Biomedical Education, New York City. The analysis of the national and New York City estimates appears in slightly different form in David Michaels and Carol Levine, "The Youngest Survivors: Estimates of the Number of Youth Orphaned by AIDS in New York City," in Carol Levine, ed., *A Death in the Family: Orphans of the HIV Epidemic* (New York: United Hospital Fund, 1993), pp. 3–12.

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The tip of the iceberg represents the 6,000 pediatric AIDS cases in the United States reported to the CDC (including the small but growing number of reported adolescent cases). Understandably, pediatric AIDS has received the most public and professional attention, since these fragile children and their families have urgent medical and social service needs. Just below the tip of the iceberg, and only partially visible above the water line, are known cases of HIV-infected children and adolescents. There are many more HIV-infected newborns than known pediatric AIDS cases (more than three times as many in 1989,[1] for example), which means that a large portion of this section of the iceberg is still hidden.

The second largest portion of the iceberg represents the uninfected siblings of the group with AIDS or HIV infection. These may be older brothers and sisters, born before their mother contracted HIV, or younger children who escaped maternal-fetal transmission. (Current rates of maternal-fetal transmission in the New York City area range from 20 to 30 percent — lower than those in Africa but considerably higher than those in Europe, for still unexplained reasons.[2])

By far the largest and most hidden portion of the iceberg is the one represented with vertical shaded lines in the graph. This portion includes uninfected children and adolescents whose parent or parents, another adult relative, or a committed caregiver unrelated by birth or marriage has either died of AIDS or is living with serious HIV disease. To carry the image one step further, the iceberg itself is situated in a stormy sea of violence, homelessness, drug and alcohol use, poverty, discrimination, and community disintegration.

Although in recent years the term "orphan" has been used most commonly to describe a child who has lost both parents, it has historically meant a child who has lost one or both parents. A definition that focuses on motherless youth was chosen for this model, partly because such a definition conforms to the realities of life as these families know it. For the vast majority of youth whose caregiving parent dies of HIV, that parent is the mother. There are, of course, families in which an HIV-infected father is the primary caregiver; however, these situations appear to be rare. There are also families in which the death of the father from AIDS, even when the mother is uninfected, is a traumatic event that results in a family breakup. Although these scenarios are important in developing programs to meet the range of individual needs, they do not affect the broad epidemiological picture.

The definition of the word orphan also conforms to the realities of epidemiologic analysis, because there are few data on the offspring of men dying of HIV disease. For these reasons, this definition is

used by the CDC,[3] WHO, and the United Nations Children's Fund (UNICEF).[4] If it were possible to estimate how many children will lose their fathers to the epidemic, the numbers reported here would increase dramatically. However, there are no statistics available for men that are the equivalent of fertility rates among women, and no one has calculated the general rate at which men father children. A series of studies of selected populations of men (in drug treatment centers, for example) would provide data to illuminate the important question of how many children will be left fatherless because of HIV.

Building the Model

The starting point for the model was the number of reported and projected AIDS deaths among adult women younger than 50. These numbers were then adjusted for the documented undercount of HIV-related mortality among women.[5] By factoring in age, race/ethnicity, and calendar-specific cumulative fertility rates, it became possible to estimate how many children these women might have borne, and when. The results were then further adjusted for decreased fertility associated with late-stage HIV disease, infant mortality, and pediatric AIDS mortality.*

This model is based on fairly conservative assumptions. For example, the middle estimate follows current predictions, which are probably overly optimistic, that the annual number of AIDS deaths will stop increasing after 1995. Most likely, these estimates understate rather than overstate the problem.

The View from the Nation

HIV has come to rival or surpass other important causes of death among mothers of young children nationally. Among women under the age of 50, cancer kills the mothers of approximately 4,200 children and 8,700 adolescents annually. Motor vehicle accidents are responsible for the deaths of mothers of an additional 3,200 children and 1,900 adolescents. By contrast, the numbers of children and adolescents annually left motherless by HIV are predicted to reach 3,900 and 3,400, respectively, by 1994.

The age distribution of these orphans is of great importance. In addition to young children, a large number of adolescents are being, or will be, orphaned. Their needs are very different from those of infants or children.

* The methods used to construct this model are explained in greater detail in David Michaels and Carol Levine, "Estimates of the Number of Motherless Youth Orphaned by AIDS in the United States," *Journal of the American Medical Association*, vol. 268 (December 23/30, 1992): 3456–3461. The estimates for cities other than New York employed 10-year rather than five-year strata.

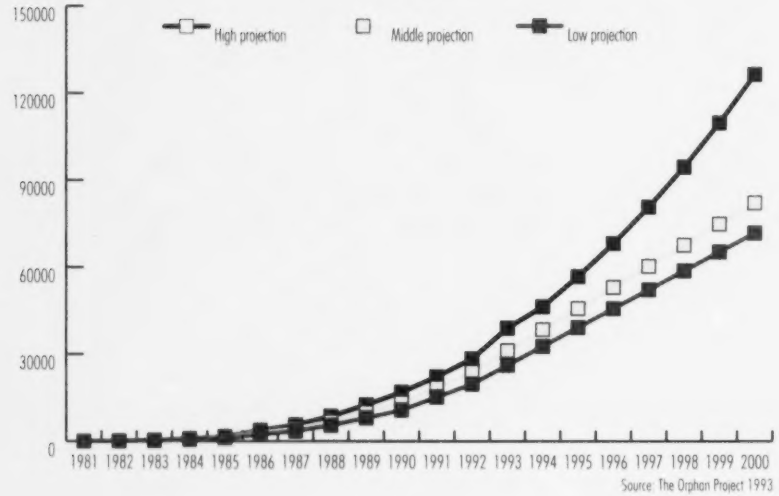
Figure 2 (facing page) shows three estimates of children and adolescents left motherless by HIV, based on a range of values for the proportions of HIV-related deaths identified on death certificates, the pediatric AIDS and overall infant mortality rates, the number of projected AIDS deaths among women in the future, and other parameters used in the model. Unless the course of the epidemic changes dramatically, the total number of motherless children and adolescents in the United States will exceed 80,000, with a range of 72,000 to 125,000, by the year 2000. Putting all these estimates together, Figure 3 (facing page) compares the six cities in terms of estimates for 1990, 1995, and 2000.

Using a different model, the CDC arrived at a similar estimate, predicting that between 93,000 and 112,000 uninfected children will be born to mothers who die of HIV between 1992 and the year 2000. Additionally, these women will give birth to between 32,000 and 38,000 children infected with HIV during the decade.[3]

The relative size of the orphan population in each city is a function of the local characteristics of the epidemic and those who are most affected by it. The estimates are influenced by such factors as the population size, the AIDS death rate in different communities within each city, and the speed in which the epidemic has spread in each community. Cities in which a large number of cases occurred among injecting drug users (IDUs) and their sexual partners (New York and Newark, for example), tend to have more infected women than cities with fewer cases among IDUs, such as San Francisco and Los Angeles. In addition, cumulative fertility rates vary with age and race/ethnicity; variation in these characteristics among the women dying of HIV in different cities will influence the estimated number of orphans, as well as the relative proportion of children and adolescents.

Figure 2

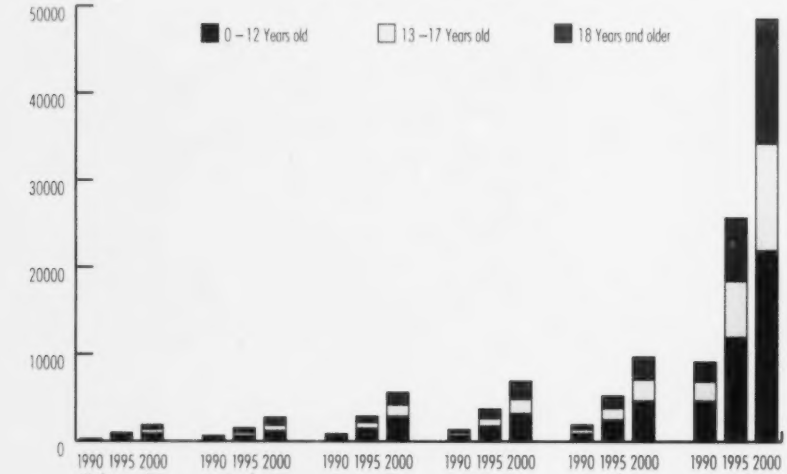
Motherless Children and Adolescents Orphaned by HIV/AIDS
Cumulative US, 1981–2000



Source: The Orphan Project 1993

Figure 3

Motherless Youths Orphaned by HIV/AIDS,Cumulative by Age Category
6 Cities, 1990/1995/2000



Source: The Orphan Project 1993

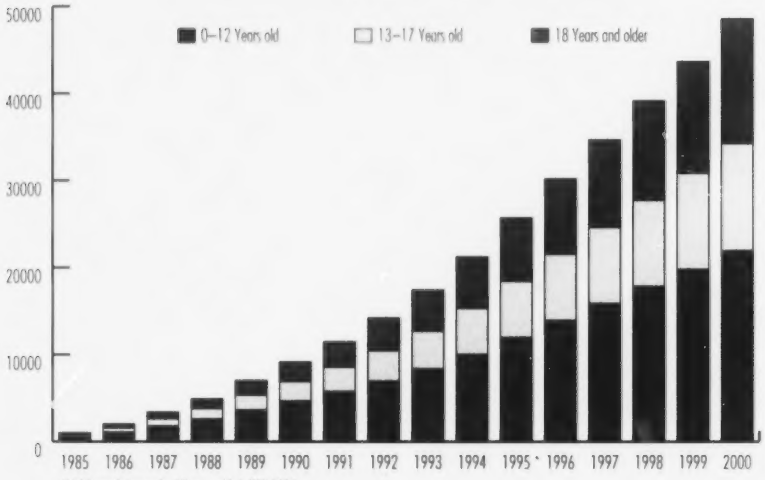
New York City New York City is the hardest-hit city in the nation. By the end of 1994, approximately 7,000 children and 6,700 adolescents will have been orphaned by HIV in New York City (Figure 4, facing page). As projections move further into the future, they inevitably become less precise; however, by the year 2000, the cumulative total is estimated to include 15,000 who were orphaned as children and another 15,000 orphaned as adolescents. The low estimate is 29,000; the high estimate 34,000; and the medium-range estimate is 30,000 (Figure 5, facing page).

In addition to these sizable groups, 25,000 young adults (18 years and older) will lose their mothers to the disease. Although the needs of this group may at first seem less emotionally compelling than those of their younger brothers and sisters, they are nonetheless significant. These young adults will also face serious psychosocial, financial, and legal problems, particularly if they assume responsibility for the care of younger siblings.

According to current estimates, more than 80 percent of the youth orphaned by HIV in New York City are offspring of women of color. The categories ("white," "Hispanic," "black") are designated by the CDC; they reflect the data made available to researchers.

Figure 4

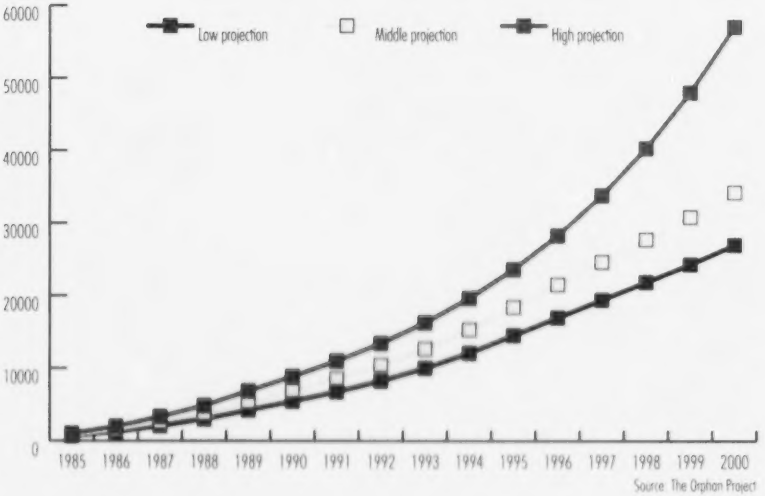
Motherless Youths Orphaned by HIV/AIDS
NYC Cumulative by Age Category, 1985–2000



(1990 population under 18 years old: 1,700,000)

Figure 5

Motherless Children and Adolescents Orphaned by HIV/AIDS
Cumulative New York City, 1985–2000

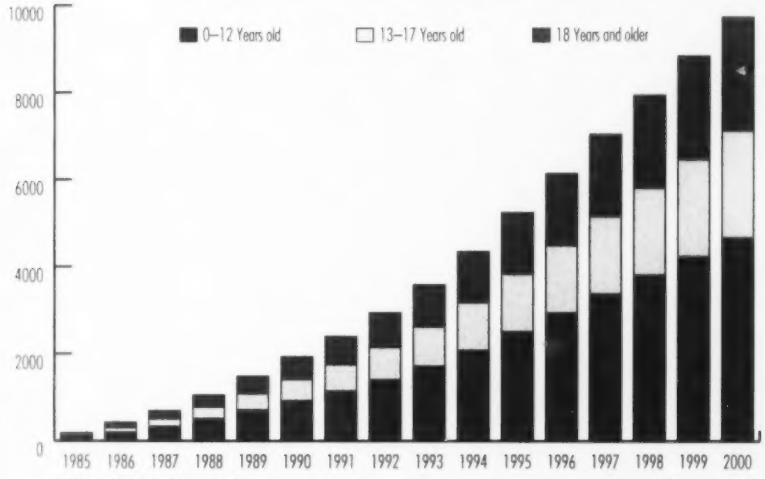


Source: The Orphan Project

Newark The city with the next highest numbers is Newark. By the end of 1994, 2,100 children and 1,100 adolescents will have been orphaned in Newark (Figure 6). By the year 2000, those numbers will reach 4,700 children and 2,500 adolescents. The estimates of the total number of orphaned children and adolescents by that year range from a low of 5,800 to a high of 11,600, with a medium-range estimate of 7,200 (Figure 7).

Figure 6

Motherless Youths Orphaned by HIV/AIDS
Newark Cumulative by Age Category, 1985–2000

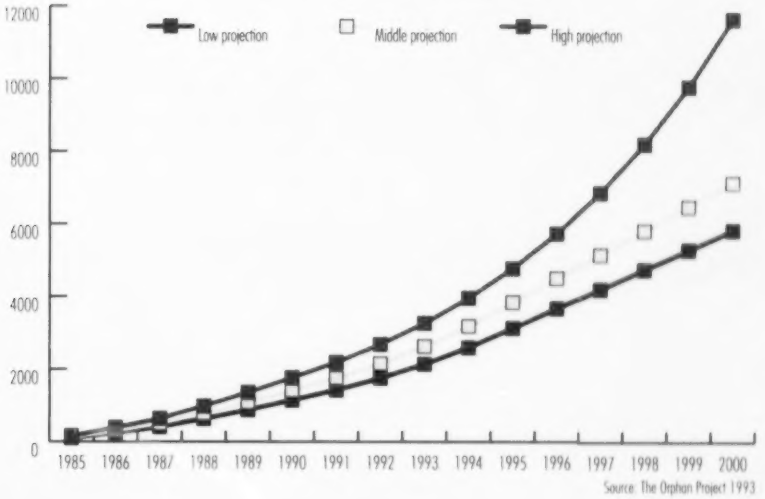


(1990 population under 18 years old: 78,000)

Source: The Orphan Project 1993

Figure 7

Motherless Children and Adolescents Orphaned by HIV/AIDS
Cumulative Newark, 1985–2000

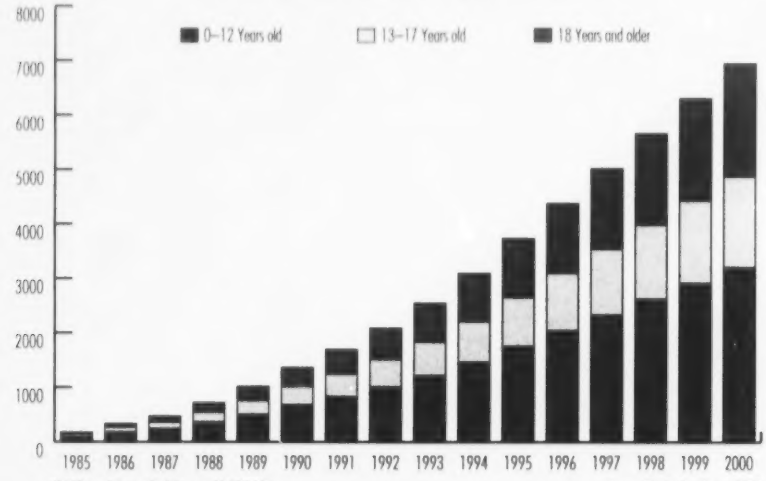


Source: The Orphan Project 1993

Miami Miami, another city with a high proportion of HIV-infected women, will have 1,500 orphaned children and 700 adolescents by the end of 1994 (Figure 8). Miami can expect those numbers to increase to 3,200 children and 1,700 adolescents by the year 2000. The range for Miami runs from a low of 3,800 children and teens to a high of 8,200, with a medium estimate of 4,900 (Figure 9).

Figure 8

Motherless Youths Orphaned by HIV/AIDS
Miami Cumulative by Age Category, 1985–2000

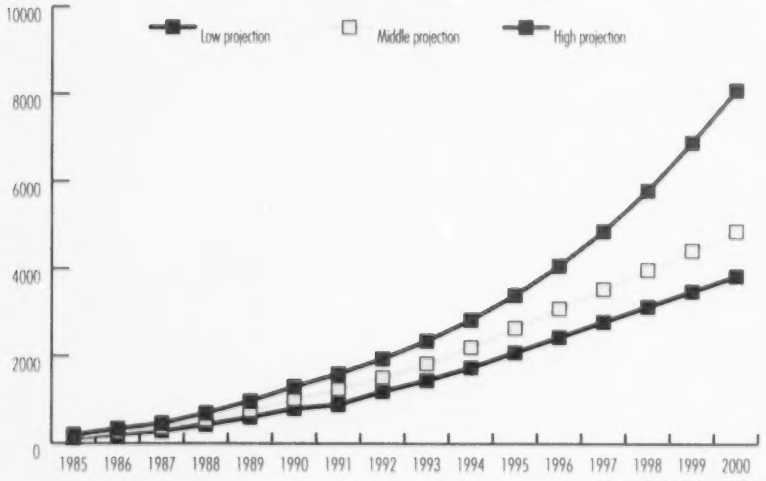


(1990 population under 18 years old: 82,000)

Source: The Orphan Project 1993

Figure 9

Motherless Children and Adolescents Orphaned by HIV/AIDS
Cumulative Miami, 1985–2000

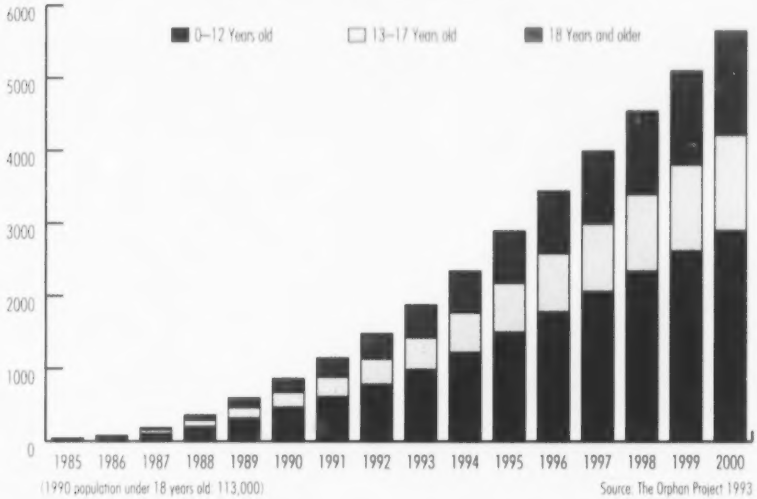


Source: The Orphan Project 1993

San Juan San Juan is not far behind Miami. About 1,200 children and 550 adolescents will have been orphaned by the end of 1994 (Figure 10). By the year 2000 there will have been 2,900 orphaned children and 1,300 adolescents. A low total estimate for San Juan is 3,300 while the high is 7,200; the medium-range estimate is 4,200 (Figure 11).

Figure 10

Motherless Youths Orphaned by HIV/AIDS
San Juan Cumulative by Age Category, 1985–2000

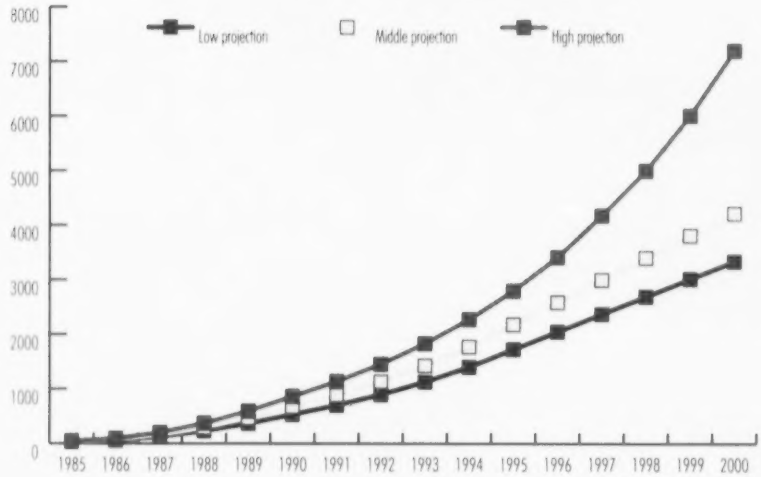


(1990 population under 18 years old: 113,000)

Source: The Orphan Project 1993

Figure 11

Motherless Children and Adolescents Orphaned by HIV/AIDS
Cumulative San Juan, 1985–2000

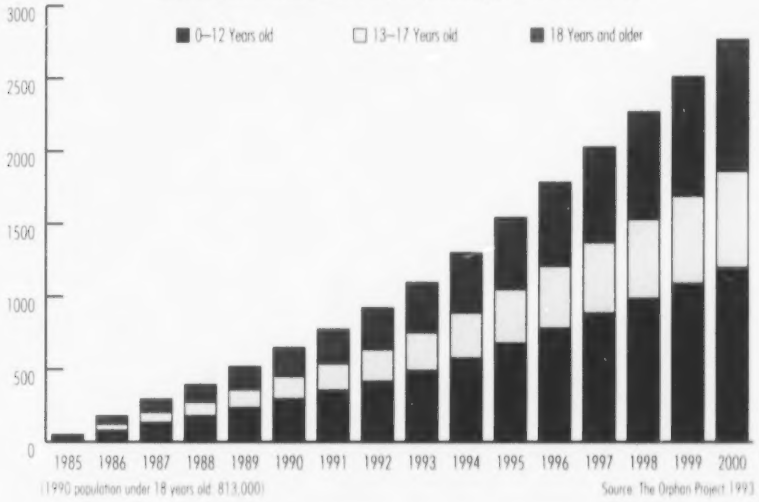


Source: The Orphan Project 1993

Los Angeles By the end of 1994, about 600 children and 300 adolescents in Los Angeles will have been orphaned, growing to 1,200 children and 700 adolescents by the year 2000 (Figure 12). The total low estimate for Los Angeles is 1,500, with a high of 3,100 and a medium-range estimate of 1,900 (Figure 13).

Figure 12

Motherless Youths Orphaned by HIV/AIDS
Los Angeles Cumulative by Age Category, 1985–2000

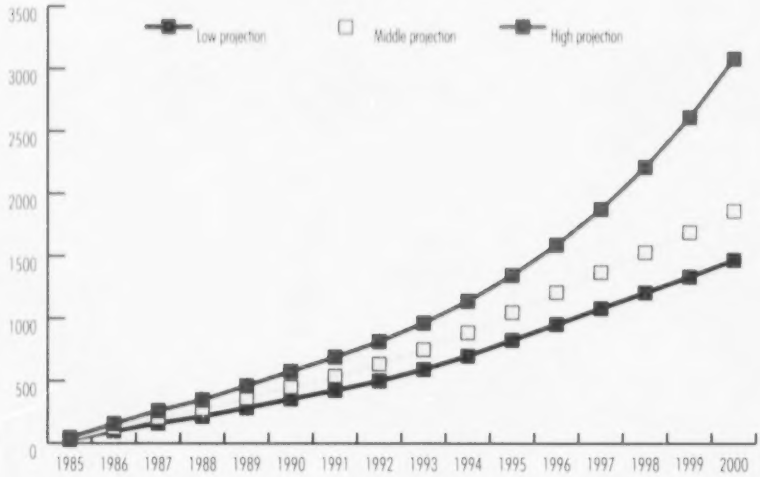


(1990 population under 18 years old: 813,000)

Source: The Orphan Project 1993

Figure 13

Motherless Children and Adolescents Orphaned by HIV/AIDS
Cumulative Los Angeles, 1985–2000

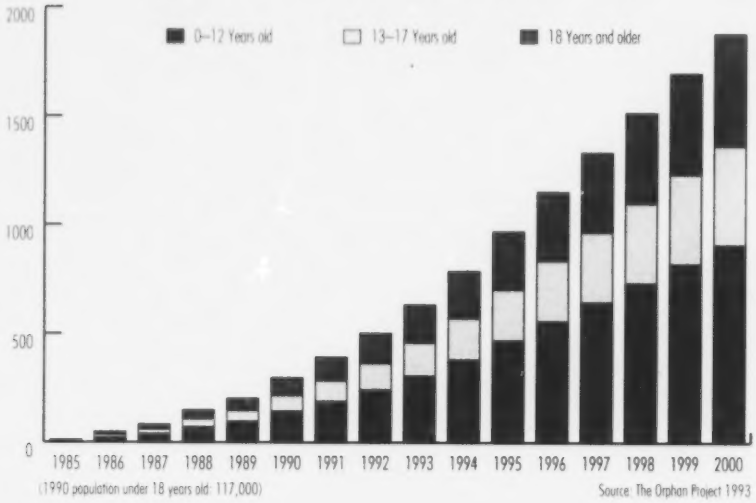


Source: The Orphan Project 1993

Washington, D.C. In Washington, a much smaller city than the other five, 400 children and 200 adolescents will be orphaned by the end of 1994; those figures will rise to 900 children and 500 adolescents by the year 2000 (Figure 14). The low estimate for the total is 1,100; the high is 2,200 and the medium-range is 1,400 (Figure 15).

Figure 14

Motherless Youths Orphaned by HIV/AIDS
Washington, D.C. Cumulative by Age Category, 1985–2000

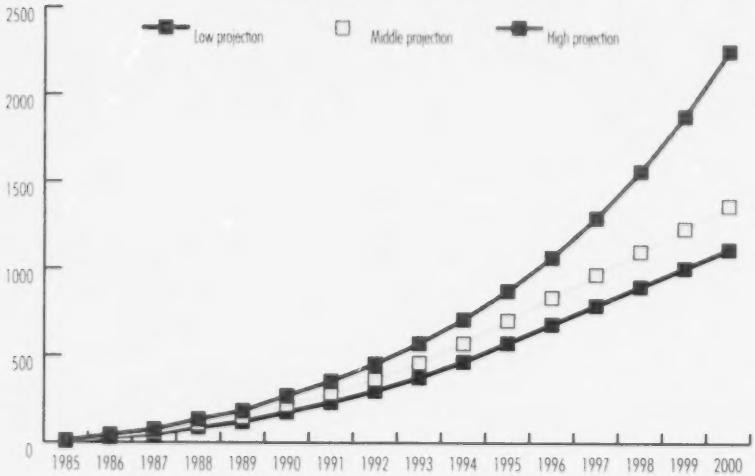


(1990 population under 18 years old: 117,000)

Source: The Orphan Project 1993

Figure 15

Motherless Children and Adolescents Orphaned by HIV/AIDS
Cumulative Washington, DC, 1985–2000



Source: The Orphan Project 1993

Future Directions

As the HIV epidemic continues to unfold, some changes may occur in the age distribution. For example, the women represented in mortality statistics so far have been mainly in their 30s and 40s. As younger women become infected with HIV and develop AIDS, the proportion of younger children who are orphaned, as well as the proportions who are HIV-infected, may be expected to increase.

Only a small proportion of youth who have lost their mothers (and often their fathers) to HIV will themselves be infected with the virus. This can be explained by examining several factors associated with risk of infection. Many of the children, and the overwhelming majority of the adolescents, were born before their mothers were infected. Of those children born to HIV-infected mothers, maternal-fetal transmission is likely to have occurred in less than one-third of the births. A significant proportion of these HIV-infected children will have died from the disease before their mother's death; the mathematical model does not include these children in the estimates of the number of orphans. As a result, the remaining number of HIV-infected orphans is small — significantly less than 10 percent of the total.

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"I will not leave you orphaned"

JESSICA THOMAS*

When she speaks of her HIV-infected children, Jessica Thomas sometimes quotes from a favorite scriptural passage: "I will not leave you orphaned." To Rhonda, her adopted daughter, and Shana, her foster child, that commitment has meant a chance for love, support, and family life.

In 1983, two-year-old Rhonda was brought to the emergency room of a New York City hospital. Her biological mother was too ill with AIDS to care for her and her foster mother moved out of the picture when she discovered Rhonda was also HIV-infected. Those were the early days of the epidemic, when AIDS was poorly understood and generated enormous fear, and it was almost impossible to place infected babies. For two years, the hospital was the only home Rhonda knew.

An alert physician recognized signs of developmental delay and depression in the stranded infant and urged hospital staff to provide more stimulation. At the time, many frightened health care professionals were actively trying to avoid physical contact with infected patients. Unwilling to see the child deteriorate, Ms. Thomas, an administrator whose job description did not ordinarily include direct involvement in patient care, began to spend time with Rhonda. Soon she was aggressively advocating for her medical and social service needs. In 1985, she decided to bring her home. "I fell totally in love with Rhonda," says Ms. Thomas. "Bells rang in my head and I said to myself, 'I can do this.'"

Initially, Jessica Thomas was denied the right to become a foster care parent because she was single. The battle to reverse that decision was only the first of many she fought with the city's social service agencies. She had to push aggressively to convince Medicaid to provide home care for Rhonda and then to persuade the Board of Education to dedicate funds allowing a home attendant to accompany the little girl to school. "I have spent days and days making telephone calls trying to figure out who does what and where the stumbling blocks lie," says Ms. Thomas in frustration. "What is missing in the bureaucracy is an ombudsman who knows the city, county, and state systems and can cut through all the nonsense."

Despite the challenges, in 1988, a year after formally adopting Rhonda, Ms. Thomas decided to bring a second HIV-positive youngster into her life. "Rhonda and I discussed it, and we decided we could share our love with another child," Ms. Thomas explains. "To be honest, I also felt I should have a reason to live if I lost my child." An infant named Shana was placed in their home as a foster child but the arrangement hit a bureaucratic roadblock. For a wrenching six weeks, Shana was in another placement.

After the appropriate paperwork was filed, the child was returned, but another five years passed before she was freed for adoption. The

*The names in this profile have been changed to respect confidentiality.

long period of uncertainty carried a heavy price for Shana, who is now seven. "She has some emotional problems," says Ms. Thomas. "That is one reason I have wanted to adopt her for so long. I believe she needs a sense of permanence."

The illness has also taken a toll on Rhonda. At the age of 12, she has survived lung collapse, grand mal seizures, and a heart condition. Her mother calls Rhonda a "miracle child" who has outlived her doctor's prognosis by many years, but she is prone to panic attacks and the intensity of her turmoil is sometimes apparent in her drawings. In one picture, she sketched a heart that is scarred and bandaged. In another piece of art, she depicted HIV as a monster, with medication in hot pursuit.

Although more responsive service systems could not vanquish all the pain her children must face, Ms. Thomas is convinced they could ease the burdens on the caregivers. "We are still acting as if our children were being raised in two-parent families," she complains. "Society needs to look at families as they exist now and design systems that work." Until accommodations are made to today's realities, the orphans of AIDS will continue to pay the price.

CHAPTER TWO

Assessing Service Needs

Parents with HIV, caregivers for children and youth who have survived their parents, and the young people themselves frequently require a broad range of services — mental health, health care, case management, legal, financial, and housing — to develop and implement an effective custody plan. Unless these service needs are appropriately addressed, the new guardians may be unable to create a suitable, secure, and stable environment for the surviving children. Without financial support and services, some otherwise acceptable arrangements may disintegrate, placing the children at risk and increasing the likelihood of foster care placement. As both a humanitarian and cost-effective measure, federal, state, and local agencies and private foundations should fund the full range of financial and support programs that families need.

Mental Health

Mental health services are a particularly urgent need. All caregivers will benefit from help in raising newly bereaved children and, if they are family members, in coping with their own emotions about the death and their new responsibilities. Families affected by HIV frequently face multiple losses, including the death of one or more family members, drug and alcohol use, community violence, incarceration, and long-distance moves. The need for supports is magnified for older caregivers such as grandparents, who are frequently called on to care for several grandchildren, and for adolescents and young adults, whose striving for independence may conflict with the responsibilities of caring for ill parents or younger brothers and sisters. Families face a host of difficult psychosocial issues: supporting HIV-infected mothers in developing custody plans; preparing surviving children for parental illness, death, and the future; disclosing HIV illness to family members; maintaining family confidentiality and appropriately disclosing a member's HIV illness; promoting the family's cultural heritage; and obtaining education/prevention services related to HIV and drug use. Mental health workers need to create a safe environment in which these issues can be discussed.

Clinicians report that although families and youth urgently need bereavement counseling, only a handful of programs exist. Mental health and health care providers should direct funds and services to grief management, targeting services to different ages and cultural

backgrounds, and for varying periods of time. The need is best met by referral to community-based services. Where appropriate, programs targeting children and youth should locate treatment and prevention services and staff training in the schools. Community and neighborhood programs targeting out-of-school youth are also essential, since many of the most vulnerable youth do not attend school regularly. Some live in constant danger on the streets.

Although few programs specialize in the psychosocial needs of this population, some excellent service models exist, such as clinics at Columbia-Presbyterian Medical Center, Beth Israel Medical Center, and the Children's Evaluation and Rehabilitation Clinic at the Rose F. Kennedy Center in New York City; the Yale University Child Study Center's Shared Parenting Project in New Haven, Connecticut; the St. Francis Center in Washington, D.C (see profile, p. 33); and the National Cancer Institute in Bethesda, Maryland. These programs obtain referrals from hospitals, foster care agencies, and case managers, and provide individual and family counseling, child and adolescent groupwork, bereavement counseling, case management, medication, and advocacy.

Clinicians are just beginning to research methods of assessing and treating HIV-affected families, children, and youth. For example, Dr. Jennifer Havens, a child psychiatrist at Columbia-Presbyterian's Special Needs Clinic in New York City, is generating data to analyze family profiles, biological and environmental risk factors, child development and adjustment disorders, and child adjustment to parental HIV illness, and to assess the implications for treatment strategies. (See profile, p. 30.) To better understand the needs of families and to enhance the quality of psychosocial services, clinicians should incorporate evaluative research into their work with families.

Recreation

Families need opportunities for relaxation and enjoyment from the many stresses related to HIV, poverty, and impending loss. Summer camps for entire families, including parents and siblings and occasionally extended family members, foster parents, and new guardians, have been conducted by organizations such as the AIDS Resource Foundation for Children (ARFC) in New Jersey (see profile, p. 42) and the Herbert G. Birch Services in New York. These camps provide parents a brief respite and a chance to develop positive, supportive memories of their families. One 11-year old, describing her camp experience at ARFC, stated to her father, "I had lots and lots of fun, Daddy. Can we stay forever?"[1] These camps offer once in a lifetime experiences for parents and children affect-

ed by HIV but are only available to a small number of families. Foundation and corporate funders should support agencies which have the capability of developing family summer camps.

Creating Memories

As biological parents die and new families are created, efforts are needed to assure that children maintain positive memories of their parents, family history, and cultural heritage. Using creative approaches, clinicians and families are producing tangible memories including videotapes, audiotapes, photographs, letters, documents of important family events, and keepsakes. One innovative model is the "Memory Store," produced by the British child welfare agency Barnardos, which provides a colorful, sturdy box with a book for recording family history and compartments for keeping tangible items that allow children to learn about and remember their parents.[2]

Transitional Services

Financial and support services are frequently needed following the death of a biological parent to help new guardians prepare a household for the surviving children. However, these services may be most difficult to obtain when they are most needed. Parents with AIDS are generally eligible for a range of programs, some of them specifically targeted to people with disabilities and/or AIDS such as Supplemental Security Income (SSI), Medicaid, rental assistance or other housing programs, special allowances, pharmaceutical subsidies, home care, homemaker assistance, and case management. Unfortunately, the funds from disability-related programs are terminated upon or soon after the parent's death. In some situations, the financial loss may be considerable.

For example, while welfare benefits and services vary from state to state, a low-income mother with AIDS who has two children in New York City may be eligible for AIDS-related monthly benefits that are significantly higher than the non-disability-related benefits generally available to new guardians. Although the total benefit package depends upon a complex family budget developed by the City Human Resources Administration, thereby resulting in different amounts for each eligible family, the table on page 29 compares the monthly benefits which may be available to a family with a parent with AIDS versus those available to the newly-constructed family:

Comparison of Monthly Benefits for Families

Benefits	Parent with AIDS with 2 Children	Newly-Constructed Family with 2 Children (Guardian not on Public Assistance)
SSI	$520.*	N/A
Public Assistance/AFDC, including:		
Rental Assistance (Enhanced AIDS rate: $480 plus $330 for each child)	$1,140.**	N/A
Shelter Allowance	N/A	$250.
Food/other Allowances	$238.	$179.
Energy Allowance	$53.	$39.50
Nutritional and Transportation Allowances	$194.	N/A
Food stamps	$292.	$292.***
Telephone Allowance	$15.	$15.
Medicaid	Available	Available for children only
Total Potential Eligibility:	**$1,932.** (amount may be reduced by agency budgeting policies)	**$775.** (amount is rounded down)

* SSI is considered unearned income that is automatically deducted from Public Assistance and considered in computing the food stamp rate; $190 of this amount is applied to the client's rent.

** Rental assistance cannot exceed the monthly rent due.

*** Eligibility for food stamps is based on total household income. $292 is potentially available to a guardian with minimal monthly income; the benefit amount decreases based upon family income.

While agency budgeting policies will reduce the actual monthly benefits depending on factors such as receipt of SSI or other monthly income and monthly rental costs, the difference in potentially available benefits for a new guardian caring for two children is up to $1,157 less than the amount potentially available for the parent with AIDS. This loss of AIDS-related assistance may significantly impair the new guardian's ability to care for the surviving children. This problem is especially significant if the guardian has a small, low-rent or subsidized apartment and cannot afford to move.

Transitional service programs would provide a crucial financial bridge in these situations. States might, for example, use existing emergency assistance programs in flexible ways to meet family needs for clothing, furniture, or transportation when a new household is being established after the death of the parent with AIDS. Families cannot, however, receive transitional or emergency support indefinitely. Innovative solutions should be sought to address long-term needs, especially housing.

Juvenile Justice Linkages

Intake personnel and youth advocates report that youth with HIV-infected family members are appearing in greater numbers before juvenile justice officials and family court judges. Youth appear before juvenile agencies on a range of charges — from Person-in-Need-of-Supervision (PINS) charges for status offenses (such as refusing to attend school or running away from home) to juvenile delinquency charges for acts that would constitute a crime if committed by an adult. Whether involved in custody or placement decisions or in juvenile justice matters, youths usually need community supports. Justice officials and judges should ensure that all youths involved in court proceedings are properly evaluated for a history of family illness and death and referred to appropriate community services, especially mental health services. Additionally, because of a shortage of resources for youth, juvenile justice officials and administrators should work with community providers, educators, and public and private funders to advocate for more youth services.

PROFILE **Columbia-Presbyterian Medical Center**

THE SPECIAL NEEDS CLINIC
COLUMBIA-PRESBYTERIAN MEDICAL CENTER
NEW YORK, N.Y.*

The Special Needs Clinic, founded in January 1992, responds to the mental health needs of children from families with HIV. Although the HIV epidemic in New York City continues into its second decade with unrelenting force, the Clinic remains the city's only "HIV-focused child psychiatry clinic." With the assistance of an anonymous donor and foundation support, the clinic has served approximately 145 children; about 100 cases are active at any given time. Its current annual budget of $150,000 supports a mostly part-time staff that includes a child psychiatrist, two clinical psychologists, a bilingual clinical social worker, and mental health trainees. One-third of the pediatric clients are HIV-infected, one-third were born to HIV-infected mothers but are not themselves infected, and one-third were born before their mothers became infected; 60 percent of the children have been prenatally exposed to drugs. Children come from the entire city, although the majority are from Manhattan and the Bronx. Most referrals come from

*This profile is based on an interview with Jennifer F. Havens, M.D., Medical Director of the Pediatric Psychiatry clinic at Babies Hospital, Columbia-Presbyterian Medical Center, on August 19, 1993.

Housing

The lack of affordable housing for individuals and families affected by HIV is a major problem. In recent years, supportive housing programs — including congregate housing, apartments for individuals and families, and rental subsidies — have been established to assist people with HIV. While resources are limited, these settings have been extremely important in assisting homeless people, preventing homelessness, and ensuring access to a range of services. Unfortunately, AIDS-related housing programs, which seek to accommodate as many ill individuals as possible, have had an unintended result: following the death of the family member with AIDS, survivors are usually required to vacate the housing unit within a short period of time.

The cutoff of AIDS-related housing assistance and the lack of adequate housing generally have been major obstacles for extended family members willing to care for orphaned youngsters. To ease the transition for surviving children and their guardians and to prevent homelessness, providers of AIDS housing should create transitional programs to assist surviving family members. Such programs would ideally permit families to live in their apartment for a period long enough to locate alternate housing, perhaps up to one year or longer. Case man-

PROFILE **Columbia-Presbyterian Medical Center**

Columbia-Presbyterian Medical Center, an AIDS-Designated Center treating adults and children, and foster care agencies that place HIV-positive children.

At the clinic's inception, families were referred to care following the mother's death, when surviving family members were in crisis. Unfortunately, such late intervention did not significantly enhance clinical outcome. Clinic staff now attempt to engage families early in the mother's illness, before the trauma of bereavement. The clinical social worker attends interdisciplinary rounds in the adult and pediatric AIDS units at Columbia-Presbyterian Medical Center and identifies families whose children are at risk for, or are already displaying, mental health problems. They are referred directly to the Special Needs Clinic; clinic staff will also see hospitalized parents. Patients who are hesitant about involving their children in mental health services are approached sensitively and engaged gradually.

Treatment includes individual psychotherapy for all family members, family therapy, medication therapy, and crisis intervention. While group work is available for children up to 13 years, the focus remains on individual therapy because of the children's strong need for individual attention. The Clinic has not started adolescent groups due to the difficulties in engaging teens in groups.

agers and support staff should additionally assist the families in obtaining an apartment and social services. Finally, public social service agencies and housing authorities should develop a range of housing services, including rent subsidies for low-income families, to keep families together and to promote the development of new, stable family relationships. These services may be coordinated with kinship care, emergency assistance programs, or a proposed financial assistance program for low income guardians (see p. 41).

Training and Education

Families affected by HIV rely on a host of professionals — nurses, physicians, social workers, psychologists, homemakers, personal care attendants, attorneys, counselors, educators, nutritionists, and clergy — to assist with their medical conditions and daily needs. Many professionals who work with families, however, have no special background or training on HIV-related matters. Some are poorly informed about HIV, uncomfortable with the issues and affected populations, and ill-equipped to handle the problems that arise.

To ensure that people with HIV and their families receive competent, compassionate, and timely care, public and private providers,

PROFILE Columbia-Presbyterian Medical Center

Research assumes an important role in clinic activities. A clinical database has been developed to collect statistics on family demography, risk factors, diagnoses, and treatment modalities. Staff research projects include: the stressors and coping mechanisms, service needs, and the effectiveness of mental health interventions with HIV-infected women and children; the cognitive functioning of HIV-positive children compared with their HIV-negative peers; and psychiatric disorders in HIV-infected school age and preschool children.

Dr. Jennifer Havens, co-director of the Special Needs Clinic, describes the increasing need for clinical services for families citywide. The "capacity of the clinic could easily be doubled with a higher budget," she says with regret and notes that staff is reluctant to do extensive outreach because the clinic cannot absorb higher caseloads. It is also difficult to recruit psychiatrists interested in specializing in community-based care for children and youth. Despite challenges of budgeting and recruitment, however, the Special Needs Clinic provides a unique model for attending to the mental health needs of HIV-affected families — a model ripe for recognition by funders, policymakers, and HIV service providers.

professional training institutes, and universities should develop a range of initiatives to train practitioners, provide continuing education, and address staff burnout. For each discipline and level of competence, education specialists should develop appropriate curricula and internships. Universities should create academic centers to enhance the recruitment and professional development of highly qualified and motivated practitioners and researchers. Finally, universities and providers should collaborate with legislators, agency regulators, and private funders to enhance the traditionally low salaries of professionals serving persons in underserved, poor communities.

Educational efforts on behalf of consumers are also important. Administrative policies and bureaucratic procedures governing entitlements, benefits, and services present formidable barriers to parents and new guardians. Some families are intimidated by the overly technical guidelines of child welfare, financial aid, and medical assistance programs. For example, the New York State Department of Social Services's *Public Assistance Source Book for Regulations* is a two-volume, several-hundred-page maze of available benefit programs, eligibility requirements, and budgeting procedures that may be too complicated for all but the best-trained bureaucratic minds. Another similarly complex volume provides

PROFILE St. Francis Center

CHILDREN'S PROGRAMS
ST. FRANCIS CENTER
WASHINGTON, D.C.*

The youngest clients involved in the children's program at St. Francis Center, a 17-year-old nonprofit bereavement counseling agency in Washington, D.C., are three and the oldest are teenagers. What they have in common is the life-altering experience of grief. "Their journeys are unbelievably painful," says Ms. Dottie Ward-Wimmer, a registered nurse and licensed counselor who works at the center with young people left behind by the AIDS epidemic. "They are literally watching their worlds disappear. Their parents, their brothers, their sisters may all be gone and often they've been separated from surviving siblings. Adults may not let them talk about their experiences and feelings because of their own discomfort and at school, all they hear are jokes about people with AIDS."

St. Francis Center counselors reach out to children with AIDS and orphaned youngsters through individual therapy sessions, play groups, and school programs. The goal is always to uncover feelings, never to bury them. "If a child says, 'My mom's a junkie,' we might say, 'That is a powerful

*This profile is based on an interview with Dottie Ward-Wimmer, coordinator of the Children's Program at St. Francis Center, on September 17, 1993.

the guidelines for the state's medical assistance programs.

Public and private providers should develop innovative community programs for family members — birth, foster, kinship, and adoptive — on agency requirements and on effective negotiation strategies to obtain needed services. In addition, agencies should simplify their inordinately complex regulations and eligibility standards. Handbooks and educational materials should be produced in language that is easily understandable and culture-specific.

PROFILE **St. Francis Center**

feeling,' or 'You looked really angry when you said that,'" explains Ms. Ward-Wimmer. "But we'd never say, 'Of course your mother's not a junkie.' That forces the child to swallow his feeling. Only by staying with a child's feelings and respecting them is he able to move on."

Private foundation grants and funds from the federal Ryan White Comprehensive AIDS Resources Emergency (CARE) Act support a host of innovative projects. One example is the Hug Club, which had its origins in an earlier effort to organize a support group. After encountering resistance from caregivers who did not want their children to know about AIDS, Ms. Ward-Wimmer negotiated with family members to develop a different approach. The Hug Club provides a safe space for children to play and talk about feelings even if they haven't been told about the realities of AIDS. Ms. Ward-Wimmer told caregivers, "'Our job will be to support your kids but it will not be to tell them that they, or someone they love, has AIDS.'"

However, if a child begins to talk about AIDS, Hug Club counselors trained in the art of reflective listening know how to respond. When one little girl asked, "Does my mommy have AIDS?" a counselor answered, "That sounds like an important question," and then encouraged her to explore her feelings. She was persistent so the counselor asked, "What would it be like for you if she did?" The child didn't get a direct answer, but she was given some tools for thinking about her situation and her mother was alerted.

Frequently, a child's questions become a launching pad for further exploration. "We have a found a way to respect these families and to walk with them down the road they want to travel," says Ms. Ward-Wimmer. "Our job is not impose our values or tell them about the 'best way' to handle this illness. If we are honestly committed to caring for these kids and

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PROFILE St. Francis Center

their families, we have to bend for them."

Play therapy is central to the approach used at the St. Francis Center. "It is a way for children to work out their issues in their own language," says Ms. Ward-Wimmer. "Children work and heal in metaphor. They don't have an adult's verbal skills." One of her young clients, whose father is dying of AIDS, grapples with fears of abandonment by play-acting with dolls. An older child hurls clay against the wall and with every throw, she is urged to express anger at something. At first, her comments were mundane — "I'm mad because I have a test at school" — but eventually she became more articulate about her rage, sometimes declaring, "I hate AIDS."

St. Francis Center sponsors several projects in schools, partially because these institutions provide ready access to troubled children and partially because grief interferes with learning. In one such program, counselors visit primary school classes in high-risk areas and use puppets and other games to help children think about AIDS, drug use, and the experience of not having a typical family. They also hold discussion groups for children who have already experienced losses and run workshops to train teachers and other staff in the issues that surround grief.

Each of the children's programs at the St. Francis Center has the same goal — to allow children to move on with their lives. "I don't believe children who are orphaned by AIDS have to be destroyed by the process, but we must do more than merely place them in foster care," says Ms. Ward-Wimmer. "These kids are sitting in the middle of a lot of pain. There are no ways around it but there are ways through it. And those ways are easier to find if you are not seeking them alone."

"Every day with my children is a day of victory"

LUIS ARCE

Luis Arce and his long-time partner, John, had many of the accoutrements of comfortable living — a spacious city apartment and a house in the country. They also had a powerful desire to bring children into their lives and the stable, nurturing environment that made it practical.

After reading about children languishing in New York City hospitals because their HIV-infected parents could not care for them, the two men paid a visit to Metropolitan Hospital in 1987. "When we saw the children on the unit, we wanted to take them all home," Mr. Arce recalls. Instead, they settled for two brothers — Noel, who was seven months old, and Joel, who was eighteen months old. A year and a half later, they added Angel, then five. Joel and Angel are both infected with HIV, but Noel is not.

Angel's personal circumstances allowed him to be adopted immediately, but Noel and Joel were in limbo as foster children for five long years. In the midst of an arduous legal struggle to adopt them, their foster parents learned they were both HIV-infected.

John was first to fall ill, and in 1991, Mr. Arce buried his lover of 16 years. Two months later, he became seriously ill himself. His family and friends rallied around to offer words of comfort and to reassure him that the children would receive good care, but Mr. Arce knew the realities of the foster care system. "People kept telling me, 'Don't worry, the children are going to be okay.' But when you have foster children, the children may not be okay. They could be sent anywhere. I'm convinced I pulled through my illness because I did not yet have a place for my children."

Rather than allow them to face uncertain futures in new foster homes after his death, Mr. Arce redoubled his efforts to win the adoption battle. Fearful of losing the children if his HIV status was revealed, he took extreme measures to disguise his illness. "It was the only way to keep my family intact," he now says. In February 1993, adoption papers were finally signed and Mr. Arce finally won the legal rights of parenthood.

With that triumph, he felt ready to deal with the realities of his illness. "I have decided to do away with evasiveness and confront the future head on," he declares. "I do have a terminal disease and there is little likelihood of beating it. But I am not a pessimist. Every day that I am able to look at the faces of my children is a day of victory against this disease. Every hour that I can spend with them is an hour of life. Every time I can plan for their futures is a time of peace."

Mr. Arce's brother and sister-in-law have agreed to adopt Noel, Joel, and Angel; steps are being taken to smooth the transition. During the summer, the children divide their time between the two homes, and ongoing family therapy allows all parties to explore their feelings and express pain and sometimes anger. Mr. Arce is at once relieved and

troubled by the arrangements he has made. "I know they will be great parents, but a father will always feel no one else can do his job quite so well," he says. At times, a sense of unfairness and regret threaten to overwhelm him. "As much as I try to be intelligent and cheerful about it, it just aches that other people are going to have the opportunity to see the things that I should see. My brother and sister-in-law will see my children graduate and go out to work and make something of their lives. I will never see those things."

The likelihood that Joel and Angel will face illness without his loving support is also painful. "When their time comes, I would have wanted to be there with them. Nobody can hold them the way I do, and no one will ever be able to make them feel as good."

Although Noel is healthy, his father believes he will shoulder the heaviest emotional burdens, and the absence of publicly funded programs to help makes him furious. "Noel will need psychological support," says Mr. Arce. "He has lost his biological mother and his biological father. He has lost John, who was his foster father, and he will lose me, his adopted father. He will lose his biological brother and his adopted brother. His whole family will be wiped out, and there is not one cent being offered from the government — no one who will say, 'I am going to help you straighten out your head.'" By sharing his own story, Luis Arce hopes to inspire compassion from the decision-makers who can help.

CHAPTER THREE

Adopting Policies and Legal Standards

Public policies and legal standards significantly influence the planning and implementation of custody plans for children and adolescents orphaned by AIDS. Although the issues related to policy and law overlap, we use "policy" to refer to guidelines and decisions that involve families and orphaned children as a group, with standards set largely by administrative agencies (or private agencies through contractual arrangements) acting under legislative authorization. By contrast, "legal standards" include substantive guidelines and procedures developed under statutes and caselaw that apply to individual family situations; legal cases frequently lead to litigation before family, juvenile, surrogate, or probate courts.

Public Policies

Child welfare policies should strengthen and promote, to the greatest extent possible, the family structures and environments in which orphaned children live. These policies should emphasize provision of necessary benefits and support services; a preference for maintaining children in their extended family, rather than with strangers; definitions of family that are inclusive and flexible enough to encompass diverse and nontraditional relationships; and permanency planning. Policymakers should not assume that families can care for surviving children without adequate resources. Nor should they create obstacles for families who are willing and able to provide such care.

Supportive Child Welfare Programs

The traditional function of child welfare agencies is to protect abused and neglected children through the development of foster care services. More recently, the emphasis has been on family preservation services designed to prevent children from being removed from the home and placed in foster care. When out-of-home placements are the result of court orders, based on determinations of abuse or neglect, parents must prove their legal fitness before they can regain custody of their children. While the adversarial aspects of this system are necessary in some cases, prior negative experiences with bureaucratic governmental structures may discourage seriously ill parents from seeking their help in planning for the future care of their children.[1]

Child welfare agencies should revise policies that may unnecessarily discourage parents from using voluntary placement services; states that do not currently permit voluntary placements should develop flexible, supportive programs. For example, parents may want to place their children in foster care voluntarily during periods of severe illness or hospitalization, but may fear the difficulty of regaining custody. Child welfare policies should ensure parents that their children will be returned as soon as their health improves. Child welfare staff will need training on this shift in agency philosophy.

Furthermore, child welfare agencies should develop supportive foster care programs that promote shared responsibilities between the biological and foster parents and permanency planning. The New York City Child Welfare Administration's Early Permanency Planning Program (EPP) offers a flexible model of foster care that can be developed and expanded by other jurisdictions. EPP was designed to find foster homes for children of parents with HIV who do not have a family member or friend able to assume legal guardianship. The program also provides support to relatives or friends who wish to take care of the children, but need financial assistance to do so.

The goal of the EPP is to acquaint children with their foster parents prior to placement, easing the transition following the biological parent's death. Unlike traditional foster care situations, EPP is flexible enough to meet the needs of terminally ill parents. Although the children continue to live primarily with their biological parent, they live temporarily with the foster parent when the biological parent is unable to provide care, such as during periods of hospitalization. When the parent is able to resume care, the children are immediately returned, without lengthy investigations or hearings. Following the biological parent's death, it is expected that the foster parent will assume care of the children and ultimately adopt them.

The privately run Second Family Program, operated by the Lutheran Social Services of Illinois in Chicago, is similar to New York City's public-agency EPP program. The program identifies and screens potential foster families and facilitates the legal transfer of guardianship or adoption, either before or after the biological parent's death. The program is designed to ensure a smooth transition for children and their new guardians by providing counseling and education, and assisting biological and adoptive families to develop ongoing, positive relationships.

Kinship Foster Care

To avoid the disruptions and instabilities that may occur if children are shifted from one foster home to another, many child welfare workers prefer to place children with extended family members. Terminology related to family placements is often confusing; professional discourse and agency guidelines use the terms kinship care, kinship foster care, private kinship care, family foster care, and foster family care, sometimes interchangeably and sometimes with differing definitions. The American Bar Association Center on Children and the Law defines kinship foster care as "kinship care [residential caretaking of children by kin] provided to a child who is in the legal custody of the state child welfare agency."[2] By contrast, we define informal kinship care as care provided by family members without any governmental intervention or monitoring.

Title IV-E of the Social Security Act (part of the Adoption Assistance and Child Welfare Act of 1980) enables relatives who meet federal eligibility requirements to receive foster care subsidies. Despite policy mandates that favor caring for children within their extended families, however, kinship foster parents who have not gone through the licensing process receive lower benefit levels than unrelated foster families in most states.[3] New York State, California, and Illinois, however, give kinship foster parents financial allowances equal to non-relative foster parents.

To maintain a stable, supportive environment for recently orphaned children and youth, kinship parents (foster and informal) often need a range of services including homemakers, health aides, respite care, mental health services, and day care. In addition, housing assistance, including rental assistance, is often critical to meet the space needs of newly enlarged families on low, fixed incomes. Support services are especially critical when older grandparents or young adult siblings, who may need assistance with childcare responsibilities, assume the parental role.

Non-Relatives as Caretakers

Generally, federal and state law narrowly define those "family members" who may assume status as kinship foster parents or who may receive AFDC on behalf of children in their care. In New York State, for example, family members must generally be specified blood and step-relatives or specified relatives through adoption to qualify under these programs; other individuals may receive benefits on the child's behalf only in emergency situations and on a temporary basis.[4] As a result, distant kin or non-relatives who are closely involved with the surviving children may not be eligible for expedited approval as kinship foster parents or as recipients of benefits on behalf of the child.

Policymakers should recognize that populations most affected by AIDS — such as the African American, Latino, and gay communities — frequently care for surviving children through "informal" adoption and other nontraditional family arrangements. For example, writing about Puerto Rican families, Nydia Garcia-Preto says, "The family is usually an extended system that encompasses not only those related by blood and marriage, but also compadres (godparents) and hijos de crianza (adopted children whose adoption is not necessarily legal)."[5] Definitions that exclude these individuals fail to consider the reality of family life for many children. Policies affecting these families should be amended to reflect a more inclusive perspective. The ABA uses an expanded definition of "kin": "Any relative by blood or marriage, or any person with close personal, emotional, or familial ties to another."[6]

Financial Assistance to Guardians

Family members and friends are frequently appointed guardians of surviving children through wills or standby or regular guardianship petitions. However, proposed guardians may need financial support to care for the surviving children. Currently, if they become legal guardians, they are ineligible to receive the financial subsidies available to foster and kinship foster parents because of a prevailing philosophy that "family members take care of their own" absent any imminent danger to the children. In New York, for example, an AFDC family receives an incremental supplement, approximately $100 per month, for each additional child. Although legal guardians may be eligible to receive AFDC on behalf of their wards, the difference between AFDC benefits and foster care subsidies may be substantial, especially for guardians caring for more than one child. In contrast, the Child Welfare Administration budgets full subsidies — at a rate of $455 to $1,345 per month (board rate plus clothing allowance) depending on the child's age and eligibility for normal, special, or exceptional rates — for each child in foster care. Appointed guardians who are willing to care for surviving children should not be penalized financially for agreeing to provide such care outside the child welfare system or for being unaware of the financial implications in doing so. There is an alternative: a subsidy program for low-income guardians, with a benefit level similar to that available to foster parents. Such programs are especially important in states that enact standby guardian laws.

Some states have embryonic programs that offer guardians foster care benefits. For example, California provides benefits to legal guardians of AFDC-eligible children under a state program, but only if the guardian is not a relative.[7] Although New Jersey usually terminates foster care subsidies to relatives if they obtain legal custody, the

child welfare agency will consider continuing services and, in very limited situations, the foster care board rate in order to maintain the placement.[8]

There are differences of opinion regarding the degree of agency supervision that should be required of guardians receiving governmental subsidies. For example, the Child Welfare League of America recommends continued agency monitoring of subsidized guardianship arrangements. One option is to amend federal regulations to allow long-term kinship foster placements with subsidies comparable to adoption subsidies; as in the case of adoptions, agency supervision would end when the placement is approved. In any case, support services should be available to families who request them.

Undocumented Persons

Foreigners living in the U.S. without legal status are known by the Immigration and Naturalization Service (INS) as illegal aliens. According to Dinah Wiley, legal services director at Washington, D.C.'s Whitman-Walker Clinic, undocumented persons are among the "classes of non-citizens who are the least likely to be eligible for public benefits."[9] Although

PROFILE AIDS Resource Foundation for Children

AIDS RESOURCE FOUNDATION FOR CHILDREN NEWARK, N.J.*

The crisis that surfaced during our interview with Terry Zealand, Executive Director of the AIDS Resource Foundation for Children (ARFC), was fairly typical. As we spoke, case managers received a report of two young children, one with AIDS, whose mother had disappeared two days earlier. Staff feared the worst: that the devoted mother, who was recovering from drug addiction, had succumbed to AIDS. Attempts were underway to find her, to contact the children's aunt, and to bring the children in for residential care. Staff also needed to notify state child welfare officials, an obligation that had to be handled carefully to avoid separating the children; current state placement practices often separate HIV-infected children from their well brothers and sisters.

Northern New Jersey has had one of the nation's highest concentrations of women with AIDS and was one the regions hit earliest by rising numbers of HIV-infected children and orphaned youngsters. Partly in response to losing a close friend to AIDS and in consultation with pediatric AIDS pioneer Jim Oleske, Terry and his wife Faye Zealand, associate director of the Foundation, established ARFC in 1987. The Foundation has become an international model of residential care and support services for children with AIDS. ARFC

*This profile is based on an interview with Terrence Zealand, Ed.D., executive director of the AIDS Resource Foundation for Children, on September 14, 1993.

undocumented persons are generally ineligible for federal benefits, they may be served by state indigent programs, such as general assistance, emergency assistance, and medical/pharmaceutical assistance (including the AIDS Drug Reimbursement Programs). In addition, the Omnibus Budget Reconciliation Act (OBRA) of 1986 allows Medicaid to pay for the care of minors under age eighteen, emergency care, and care for pregnant women, regardless of immigration status.[10]

Despite the potential availability of state-funded programs for noncitizens and the eligibility of minors for Medicaid, undocumented persons who apply for public benefits or services may diminish their opportunities to attain legal status or even risk deportation. Some programs share information with the INS and Congress has recently reaffirmed its intent to exclude HIV-infected immigrants from obtaining status as lawful permanent residents.[11] Public benefits programs should allow children of undocumented persons, regardless of their status, to obtain equal access to services. Most importantly, undocumented parents should not be penalized in any way, including being reported to the INS, for attempting to obtain care or services on behalf of their children.

PROFILE **AIDS Resource Foundation for Children**

currently offers transitional residential services for children with HIV at three St. Clare's Homes — named after the patroness of children in distress — in Elizabeth, Jersey City, and Neptune. The Foundation accepts referrals from area hospitals and cares for children until they can be reunited with their families or placed in foster homes. More than 135 children have received care at the homes, which have a total of 18 beds. Although most children are under three years old, children up to 12 have lived at a St. Clare Home; stays range from one week to two years. During the summer of 1993, the homes operated at 100 percent occupancy, but occupancy rates vary; empty beds are often used for respite care.

Each St. Clare's Home has a house manager, an assistant manager, a part-time social worker, an on-call nurse, an attending physician, and eight full-time and four part-time child care workers to provide around-the-clock services. Like most AIDS organizations, ARFC relies heavily on volunteers; each home has eight to twelve trained volunteer child care workers.

In addition to its residential facilities, ARFC provides a full range of support services for family members at the Newark-based Haller House. Services include individual and family counseling; bilingual support groups; family social evenings; bereavement groups; food, clothing, and transportation services; adolescent programs; a quarterly newsletter; volunteer and staff training; and educational programs. The community support program eases the transition from hospital to community settings

Legal Standards

The legal system weighs heavily on the lives of families affected by HIV. Courts are involved in decisions about custody for surviving children, custody disputes, interstate placements by child welfare agencies, consent to children's medical care, and the rights of adolescents. Despite the legal system's pivotal role in the day-to-day activities of families, it is ill-prepared to meet its responsibilities. Few attorneys are trained to represent poor HIV-infected parents and their children. Family court judges and surrogates are often uninformed about the impact of HIV disease on family life. Family courts, already overwhelmed with large numbers of troubled families, are unprepared to deal with growing caseloads of orphaned children. Parents may not understand the legal implications of apparently straightforward child care decisions.

Custody Planning

Arranging for the future care of their children is among the most difficult legal and psychosocial issues facing women with HIV. Before parents are able to develop custody plans, they may experience a range of emotions, typically

PROFILE **AIDS Resource Foundation for Children**

through discharge planning, follow-up after family reunification or foster placements, training and support services for foster parents, respite care, and emergency placement. A free residential summer camp program for the entire family provides a brief vacation from daily stress.

Since its inception, the Foundation's annual budget has grown from $150,000 to more than $2.7 million dollars. Services are funded by a $1 million contract with the New Jersey Division of Youth and Family Services, as well as by Title I of the Ryan White Comprehensive AIDS Resources Emergency Act, Medicaid, the New Jersey State Health Department, foundation support, and private donations.

Developing additional resources for children and youth orphaned by AIDS is a growing priority for the Foundation. This past year, the Newark and Jersey City facilities developed support groups for teens with HIV-infected family members. The summer camps have provided a place for creating family memories, such as photographs and videos, for surviving members. To promote the needs of orphaned children, Dr. Zealand believes New Jersey should re-examine its child welfare policies; he emphasizes the particular need for guidelines on kinship care, legislation on standby guardianships, and a commitment to keeping families (including HIV-infected and well siblings) together.

including denial, fear, and anger. Some, perhaps most, never address the planning needs of their families. However, social workers, case managers, and attorneys who are sensitive to parental fears and concerns, straightforward in their explanation of options, and persistent in their discussions are usually able to guide HIV-infected parents through this difficult process.[12]

Existing custody planning mechanisms, which vary by state, do not generally meet the needs of parents with terminal illnesses. While alive, parents can either name guardians in their wills to become effective upon death or file a guardianship petition to transfer most caretaking responsibilities following a court hearing. Neither option is ideal. If a guardian is named in a will, a parent cannot be assured that the choice will actually be honored by the family court judge or surrogate, who has wide latitude in deciding the best interests of the child. If parents choose guardianship petitions, they relinquish important decision-making rights and perhaps physical custody of their children.

To create a more flexible option, New York State enacted a Standby Guardian Law in June 1992 to allow terminally ill parents to name a guardian effective at the time of physical or mental incapacity or

PROFILE **University of Miami School of Medicine**

DEPARTMENT OF PEDIATRICS*
UNIVERSITY OF MIAMI SCHOOL OF MEDICINE
MIAMI, FLORIDA

From a patchwork of public and private funds, the Department of Pediatrics at the University of Miami School of Medicine has woven together an ambitious program of research, patient care, and counseling targeted at children with HIV and their families. Through its affiliation with Jackson Memorial Hospital, the county hospital that treats the majority of Dade County's pediatric HIV cases, researchers study perinatal transmission, the natural history of AIDS, and the physiological development of HIV-infected children. Physicians and social service professionals provide cutting-edge medical services, primary care and a full range of psychosocial support, case management, and referrals. Jackson Memorial's commitment to family-centered care is bolstered by a nine-bed, dedicated HIV pediatric unit that allows parents to stay close to their children.

The orphan problem first came to the hospital's attention in 1984, when it could not find a place to discharge "Baby Pumpkin," an HIV-infected infant whose mother had died of AIDS. "Good Morning America" featured a segment on the child and worldwide attention followed. The

*This profile is based on an interview with Ana Garcia, a licensed clinical social worker at the Department of Pediatrics of the University of Miami School of Medicine on September 21, 1993.

upon their death. Florida, Illinois, and California have passed similar laws; other jurisdictions, including Maryland, Pennsylvania, and Washington, D.C. are considering them. Representative Carolyn Maloney of New York introduced a bill in the 1993 Congressional session (H.R. 1354) to require states accepting federal payments for foster care and adoption assistance under Title IV of the Social Security Act to enact standby guardian legislation.

In New York, standby guardian designations may be made at a hearing before the family or surrogate court or in a written statement, which must be filed with the court by the proposed guardian after the parent becomes incapacitated or dies. Because judges have such broad discretion, family law attorneys suggest that written designations, which only delay the court hearing, may not assure the judge's approval of the proposed guardian, perhaps defeating the purpose of this law. While passage of standby guardian laws in all states should be a legislative priority, legislators should evaluate the New York experience.

On October 18, 1993, The Orphan Project sponsored a meeting with family court judges, surrogates, attorneys, social workers,

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media blitz helped social workers find an appropriate foster care home and, more importantly, focused a lens on one tragic footnote of the AIDS epidemic.

"After Baby Pumpkin, we began to identify boarder babies as a mounting problem," says Ana Garcia, a clinical social worker who develops new programs and special projects for the Pediatric AIDS Program. The hospital's initial response was to convert an inpatient unit to a nursery for hard-to-place children; eventually, many of the nurse's aides and practical nurses caring for the children were licensed to bring them home.

It is now standard practice at Jackson Memorial to identify the pediatric patients, as well as the children of parents receiving care in the hospital or its clinics, who are at risk of becoming orphans. Ms. Garcia is involved in developing care plans and making other advance preparations and has learned to ask for personal mementos that she can pass along. "Children keep these things and treasure them when their parents are gone," she says.

If the children are not infected with HIV, Ms. Garcia makes a point of talking to their guardians about prevention. "I tell them, 'Make sure your kids know about HIV. It would be tragic if they became infected from

advocates, and family members to examine how the law has been implemented and to make recommendations for enhancing its application. Among the issues that should be considered by other jurisdictions contemplating standby guardian laws are: designating versus obtaining court approval for proposed guardians; determining which disabled individuals may nominate standby guardians; granting temporary letters of guardianship pending child abuse and criminal clearances; limiting the adverse financial impact of standby guardian status; and granting seriously ill guardians the authority to nominate successor guardians. In addition, other states should coordinate attorney, social worker, and judicial training, as well as community outreach, with attempts to enact standby guardian legislation.

Custody planning can only be effective if attorneys are trained to work with women with HIV in the poor communities where most of them live. Public and private funds are needed to develop and expand legal services targeted to women and families affected by HIV. Moreover, all legal service programs for people with low incomes should develop services needed by the HIV-infected community. Funding should be available for school loan forgiveness programs, salary enhancements, and other incentives to encourage attorneys to work in poor neighborhoods.

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high-risk behavior in later years after being lucky enough to miss the virus the first time around.'"

Ms. Garcia is the first to admit these efforts barely scratch the depth of the problems facing orphaned youngsters. Like most service providers, she is frustrated by the dearth of adequate services. "We have a great opportunity to intervene with mental health support, but this is not a social priority. The affected kids who are HIV-negative get the short end of the stick. They are not being told why they have lost their families. They are not given an avenue to express anger and sadness at their abandonment and isolation." Ms. Garcia is convinced that society will suffer for allowing their emotions to be buried. "These kids will eventually act out their feelings. When are we going to address their needs? When they are already criminals?"

Because the orphan issue is not being addressed comprehensively, spotty funding often creates problems. For example, Ms. Garcia says she must sometimes explain why substantial state and private subsidies are available to licensed foster families but not always to the grandparents and aunts who assume custodial responsibilities. "These relatives may be appropriate caregivers but if their homes aren't considered eligible for

Interstate Placements

Following the death of their parents, and in some cases during the parents' lives, some children are placed with family members in other states or in Puerto Rico. All states participate in the Interstate Compact on the Placement of Children, which sets out the responsibilities of state child welfare agencies sending children to other states, as well as the responsibilities of the receiving states.* Most importantly, the sending state retains jurisdiction, including financial responsibility, for the child.

Nevertheless, problems remain. Childcare professionals and advocates report difficulties involving the sending state's acknowledgement of financial responsibility; conflicts over the receiving state's monitoring and supervisory responsibilities; disputes about how much information the receiving state needs to place the child appropriately; and jurisdictional conflicts between family courts. Problems are not limited to long-distance placements. Christine Monahan of the New Jersey Office of the Law Guardian in Newark recounted the challenges in

*As of 1993, all 50 states, Washington, D.C., and the Virgin Islands have ratified the Interstate Compact on the Placement of Children; Puerto Rico and Guam are not parties to the Interstate Compact.

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licensing, they can't access kinship funds, and this creates tremendous anger and frustration."

Policies that separate siblings are another example of the hard choices that get made in the face of limited resources. Social workers at Jackson Memorial usually refer HIV-infected orphaned children to Project Smile, which recruits, trains, and supports foster families willing to deal with the complexities of AIDS. The reluctance to place healthy HIV-negative children in these homes is understandable, but the consequence — a splintered family unit — satisfies no one. What is worse, says Ms. Garcia, is that no one tells the children where their siblings have been placed and why they have been separated.

Despite the service gaps it encounters, the Department of Pediatrics makes all the links it can for orphaned youngsters, regardless of their HIV status. "We're master of referrals," says Ms. Garcia. "The magic word is 'collaboration.' But when the services just aren't there, it is the children who pay the price."

resolving a dispute that involved the placement of children from Newark with family members just across the Hudson River in New York City.

Since the start of the HIV epidemic, ill individuals and their families have frequently travelled to and from Puerto Rico and states such as New York, New Jersey, and Florida to access the generally higher level of care and services available on the mainland and to stay with extended family members. Puerto Rico, however, is not a participant in the Interstate Compact because of the financial responsibilities related to conducting home studies and supervising children sent to and received from other states; this results in case-by-case placement arrangements.[13] Formal guidelines should be developed between Puerto Rico and, at the minimum, states with large Puerto Rican communities.

Alice Shotton, a youth law attorney, suggests that a major problem faced by state compact administrators is "their inability to enforce compliance with the compact."[14] State legislatures and social welfare agencies should develop new guidelines to enforce interstate compacts and expedite out-of-state placements. In many cases, this may involve amending state legislation to tighten and enforce the responsibilities of the sending and receiving states. Furthermore, time frames for placement should be incorporated into placement agreements. For example, Ms. Monahan recommends that initial contacts for placement be made within thirty days of referral and that the child placement agreement be executed within ninety days. Placement procedures should also promote interstate communication among family court judges and child welfare caseworkers.

Family and Juvenile Courts

Even before the HIV epidemic, family courts, especially in large metropolitan areas, were overwhelmed with cases involving child abuse and neglect, juvenile justice, and custody, placement, and visitation disputes. HIV has magnified the crisis in large cities, as family court judges, and in some cases probate judges or surrogates, begin to deal with orphaned children and youth. Although most cases involve the placement of surviving children, some courts also hear abuse and neglect cases.

Social workers and attorneys working with youth are beginning to link HIV-related family losses and juvenile justice issues (see page 30). Recent anecdotal evidence suggests that HIV-affected youth are coming to the attention of juvenile justice agencies in greater numbers, with presenting problems ranging from truancy and other status offenses to more serious criminal offenses involving drugs and violence. Furthermore, in a study of adolescents from 40 families with AIDS conducted by New York City's Division of AIDS Services, researchers found

that 25 percent of the young men had been arrested or had serious problems with the police, including three who had been jailed. Thirty-four percent of the teenagers interviewed were truant, suspended from school, arrested or on probation, or defiant of parental rule-setting; 73 percent had problems in school.[15]

These reports raise a host of difficult and complicated issues. If judges are aware of a family's history of HIV, they should use that knowledge appropriately. Among the questions raised: How can the child and family system be supported to prevent harmful behaviors? How can community resources be used most effectively? If the child's parents have died or are incapacitated, does he or she have an effective advocate in court proceedings? Does the parent's illness play a role in the child's behavior? How can judges avoid using this information in a discriminatory manner? On the other hand, if the HIV status of the child or family members is not known, is this information relevant? Should HIV status routinely be disclosed? To answer these questions, more community resources, research, and policy analysis are vitally needed.

Judicial training programs to prepare family court judges for HIV-related cases should be developed on the legal, medical, and psychosocial needs of families affected by HIV. To complement these training efforts, new benchbooks (compilations of legislation, caselaw, and court procedures for judges) and guidelines are needed to assist judges in making custody decisions. States must assure that family courts have the financial and staff resources to hear the growing number of HIV-related cases in a timely manner.

Issues for Adolescents

The frequently uncertain legal status of adolescents and the general lack of youth services require particular attention. While young children are usually desirable candidates for adoption by extended family members or non-relatives, teenagers can be difficult to place. Adolescence is a difficult period, as teenagers undergo significant physical and emotional changes while striving to achieve independence from their parents and families. These challenges are compounded by the multiple losses that many youth with HIV-infected parents encounter — losses related to drug use, community violence, incarceration, and having other family members with HIV. When grief is not expressed, some teenagers may internalize these losses and become depressed or anxious. Others may react through alcohol and drug use, sexual activity and prostitution, and criminal activity. Many potential caregivers prefer not to assume such difficult parental responsibilities, especially if younger children also require attention.

Placement options must be developed for teenagers. If desired by the teenagers, all efforts should be made to maintain them with their younger siblings. To be successful, a range of supportive mental health services, including bereavement counseling and family therapy, should be available for the new family unit. Teenagers who have assumed caretaking responsibilities for ill parents and younger siblings often have special needs. For hard-to-place youth, small, non-institutional, supportive group living settings will be necessary. Options for supervised, independent living for older teenagers and planning for adulthood must also be explored.

The legal rights of adolescents remain murky. The National Center for Youth Law in San Francisco has been a leader in advocating a coherent youth policy. Currently, a patchwork of state legislation grants mature youth the right to consent to particular health care procedures; confidentiality is protected to varying degrees. With greater numbers of adolescents living in quasi-independent situations, the decision-making rights of mature youth must be broadened so they can obtain necessary services, including preventive and routine health care, and make other important life decisions. New state legislation may be necessary, and advocacy with legislators and program administrators is needed. Additionally, public and private sector funding is needed to develop youth advocacy initiatives that promote youth-centered policies and programs and provide ombudsman and legal services to meet individual needs.

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"If we are going to lean on women to take care of children and grandchildren, we have to make it easier for them."

RUTH BEZARES
MOTHERS OF CHILDREN WITH AIDS

Ruth Bezares's personal and professional life is intimately connected with AIDS. She lost her daughter to the epidemic two years ago and has cared for her five-year-old granddaughter since the child's birth. "It was a big shock to learn that my daughter was infected," Ms. Bezares recalls grimly. "I had a friend with AIDS so I knew something about the disease, but I was very concerned about how my family would perceive it. On some earlier occasion, I heard a family member say, 'People with AIDS deserve what happens to them,' and I was fearful of encountering that sort of reaction again. Even my pediatrician warned me to expect discrimination."

In 1990, the pressures of her own situation led Ms. Bezares to research the services available to caregivers of people with AIDS — and to discover they were almost nonexistent. Within a year, she had founded Mothers of Children with AIDS (MOCA) with the help of a small grant from the New York State AIDS Institute and the donation of free office space from the Episcopal Mission Society. The agency now runs two support groups for caregivers, one in English and one in Spanish, and maintains referral lists for clients who need additional services. Another primary function is to provide education about the course of AIDS. "People need to understand the trauma of living with AIDS or surviving the death of a parent," says Ms. Bezares. "A client will say to me, 'I don't understand my son. One day he looks well, the next day he looks like he is dying. Sometimes he is rude or he screams at me.' They need to know that this typical of the disease."

At support group meetings, the absence of appropriate services, and the challenge of accessing the ones that exist, is discussed over and over again. "In experiencing the issue of HIV and AIDS with my own daughter, and certainly in listening to the moms who come to my group, I know the support systems just aren't there," says Ms. Bezares. "If we are going to lean on women to take care of children and grandchildren living with AIDS, we have to make it easier for them. What the system now does is make it harder."

Before any new programs are designed and implemented, however, Ms. Bezares believes passionately in the need to consult the community of people who will be affected. "You can't take old models and try to fit us into them. Programs have to make sense to the people they are serving. Service providers, hospitals, social workers and doctors cannot speak for us. They have to listen to us. What they can do is to provide a service based on what we tell them our needs are, not based on some model that was created

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for other purposes. Otherwise, we are just spinning our wheels."

The shortcomings of the foster care system is a source of particular frustration for Ms. Bezares. "The system hasn't caught up with today's realities. There is a whole generation of children in foster care who were born under the AIDS epidemic, but old procedures are still being used." In particular, she rails against the absence of authority for foster parents. "We are not people to be used for the convenience of the system. Our homes are not places where kids can be dumped. If a foster parent is good enough and trusted enough to care for a child, then she has to be able to participate in the decisionmaking process. Right now, we are not allowed that right and that is unconscionable."

When Ruth Bezares takes off her professional hat, she faces the challenges of AIDS on a very personal level. Her granddaughter, who is not HIV-infected, draws in an HIV coloring book and hears the subject discussed at meetings in their home. Although she is not old enough to understand the full dimensions of AIDS and what it means to her life, she does know that her mother was very ill before her death and sometimes the little girl says, "I have two mommies." Through her efforts to make the system more responsive, Ruth Bezares hopes to ease, at least in some small ways, the struggles that may lie before her and others.

CHAPTER FOUR

Developing an Agenda for Research and Policy Analysis

While actions can and must be taken now to assist children, adolescents, parents, and caregivers in families with AIDS, future policies and programs will benefit from a more solid research base. Important information that will help policy makers and program developers is lacking in several areas:

Further Research Needs

1. Epidemiology

The Orphan Project has generated substantial epidemiological data projecting the scope of the problem of children and youth orphaned by AIDS. The national and local data published in the *Journal of the American Medical Association* and in this report provide the most comprehensive estimates currently available on the impact of the HIV epidemic on the next generation. The Centers for Disease Control and Prevention (CDC) have also estimated the size of the orphan population and its figures are essentially similar. Further refinements are necessary to take into account the lack of data on fathers; to track demographic changes in the epidemic, as well as other related variables, including levels of family income and the availability of public or private health insurance coverage; to explore the impact of treatment advances on mortality as the standard of HIV care is refined during the 1990s; and to estimate the numbers of children at each age level, rather than to make only cumulative projections of children and youth.

2. In Whose Care and Custody?

Information is needed on what happens to children and youth whose parents die of AIDS. There has been no analysis of who cares for children and youth immediately after the parent with AIDS dies and no information about whether this initial arrangement is short-lived or permanent. Providers report that few parents actually complete formal custody plans. In New York City, only half of parents make custody plans.[1] Similarly, data are lacking on the number and ages of children who enter regular foster care or kinship foster care following a parent's death; on the legal status of new guardian arrangements; and on the number of siblings who

are separated, either in extended families or in foster care. In collaboration with The Orphan Project, New York City's Human Resources Administration Division of AIDS Services (DAS) is currently examining closed and open family cases to answer these questions; DAS and The Orphan Project will release an analysis of these cases in 1994.

3. The Suburbs and Rural Areas

While large metropolitan areas have developed a range of responses to the HIV epidemic and received substantial federal, state, and local funding through the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, CDC grants, and Health Resources and Services Administration (HRSA) demonstration grant programs, smaller cities and rural areas are less prepared to care for HIV-infected people in general, let alone to meet the service needs of surviving children and youth. Research is needed on the growing number of youth orphaned by AIDS living in and moving to suburban and rural areas, where the diversity of services found in larger cities may be lacking and where HIV-affected families may be more stigmatized.

4. Cultural Milieu

How families react to life-threatening illnesses, death, drug use, sexuality, and poverty is influenced by cultural background. Ethnicity, race, religion, political and philosophical beliefs, and sexual mores all play a role in how families cope with HIV and develop custody plans for surviving children. Anthropologic and ethnographic studies are needed to describe the cultural milieus of families and how community factors affect custody arrangements.

5. Adolescents' Capacity to Consent

State legislation frequently permits mature or emancipated minors to consent to specified health care or mental health services or to participate in research. Because these laws often vaguely rely on the "capacity of minors to consent" to care or research without providing further guidance, providers are sometimes reluctant to offer care. Studies are needed to examine the characteristics of adolescents without parental supervision who can effectively give consent. The characteristics of youths caring for their ill parent and younger siblings should also be explored, even though there is disagreement as to whether these arrangements are appropriate. In addition, research is needed to assess the mental health needs of children and adults affected by HIV and to measure outcomes of psychosocial interventions.

6. Bereavement

Loss of a parent is one of the most difficult psychological traumas children and adolescents can face. How they mourn for their parents may have significant implications for their future adjustment. For example, some providers report a link between violence, acting out, and adjustment disorders among adolescents with unaddressed grief. Studies are needed to examine bereavement in youngsters of different cultural backgrounds and ages and to determine which factors promote or impede the healing process.

7. Service Access

Families receive services in a variety of settings: hospitals, community clinics, and offices of private physicians; public child welfare agencies; AIDS service organizations; voluntary child and family service, foster care, and adoption agencies; mental health centers and counseling agencies; and elsewhere. The location of services has implications for funding, program development, and policy analysis. To promote accessibility, data are needed on where and how families obtain services. Particular attention should be paid to how adolescents access services since many do so independently.

8. Documenting Family Histories

Children and youth orphaned by AIDS need tangible memories of their biological parents and families, and their cultural heritage. Vehicles such as videotapes, letters, photographs, and "Memory Stores" document family histories. Psychosocial research should be conducted to determine the best strategies for documenting parents' life stories and family histories in personally meaningful ways.

9. Family Confidentiality and Disclosing HIV Information

Maintaining the confidentiality of HIV-related information and deciding how and to whom to disclose HIV status is one of the most difficult challenges facing infected individuals and their families. Psychosocial research should examine patterns and consequences of HIV disclosure within and outside the family and among various communities and cultures.

Issues for Policy Analysis

1. The Ryan White CARE Act

The federal Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 has been among the most significant governmental funding bills to authorize health care and support services for "individuals

and families with HIV disease." Through yearly appropriations, emergency funding is provided directly to metropolitan areas that are disproportionately affected by the HIV epidemic (Title I) and to the states (Title II). Policymakers and advocates should consider the applicability of the CARE Act to services for well family members and examine possible amendments in proposals to reauthorize this legislation, which expires in fiscal year 1995.

2. Interstate Compacts

To ease interstate placement of children, more information is needed on the role of the Interstate Compact on the Placement of Children and on factors that complicate placements, such as differing benefit levels for foster parents and the availability of kinship foster care. Strategies that might expedite interstate placement and enforce agreements between states should also be analyzed. Since placements to and from Puerto Rico are developed on a case-by-case basis, preparing case studies will illuminate the relative effectiveness of, and obstacles presented by informal procedures, compared to interstate agreements.

3. Benefits and Entitlements

The types of family arrangements created by custody plans have a direct impact on the benefits available to new caretakers, which vary considerably by state. For example, a grandparent approved as a kinship foster parent will probably be eligible for significantly greater financial benefits than one who became a legal guardian. Similarly, an analysis of the impact of the loss of disability and AIDS-related benefits following the death of the ill parent has important implications for newly constructed families. The Orphan Project will release an analysis and recommendations on the relationship between custody plans and benefit programs in 1994.

4. Kinship Foster Parents

Although a consensus is building among child and family advocates that non-relative foster parents and kinship foster parents should receive comparable financial assistance and other services, the states — with exceptions such as California, Illinois, and New York — have generally lagged behind. State-by-state analysis is needed on the availability of formal programs and subsidies to assist kinship parents and on certification and monitoring requirements and other policies.[2] Cecelia Sudia, a family services specialist with the Children's Bureau of the federal Department of Health and Human Services, reports that the Bureau is supporting a continuing

study of state kinship care policies and is preparing a request for proposals to undertake a comprehensive analysis of subsidies for kinship foster parents.

5. The Legal Concerns of HIV-Affected Youth

Youth workers have emphasized the difficulty of meeting the service needs of adolescents due to the conflicting, confusing, and underdeveloped patchwork of state laws granting teenagers decisionmaking authority. As more youth are orphaned by AIDS, the need to develop a consensus on the abilities of teenagers to obtain services for themselves, and to enact state legislation to address current gaps, becomes more apparent. In addition, the relationship between AIDS-related loss among youth and the juvenile justice system needs to be documented in order to secure greater public and private funding for comprehensive, community-based youth services.

Areas Where Conflicting Views Surfaced

At the meeting that formed the basis for this report, three subjects arose at various times and generated considerable discussion and disagreement. The issues have been debated in different contexts throughout the AIDS epidemic but take on new nuances in discussions about families and children.

1. Disclosing the Parent's HIV Status to Children

Deciding whether or not to disclose HIV status to other family members, and especially to one's children, is one of the most difficult psychosocial choices facing parents with HIV. This raises a predicament: should disclosure of HIV status within the family, and especially to children, be strongly encouraged by professionals, supported but not encouraged, or left solely to families' discretion?

There are no easy answers. Parents must weigh the importance of open communication within the family against the possible harmful effects of early disclosure, particularly when young children are involved. Frequently, children — especially older children and adolescents — know of, or strongly sense, their parent's illness. Moreover, maintaining family secrets is often emotionally draining. On the other hand, parents are generally the best qualified to assess their children's ability to handle distressing news and to be discreet in talking outside the family, and are best able to determine when and how to disclose their illness. While professionals should, in most cases, support and encourage parents to disclose their HIV status or the gravity of their condition to

their children in an age-appropriate manner, there may be times and situations when such disclosure would be harmful. In such cases, professionals should sensitively explore with parents alternatives to disclosure and together determine the approach that best supports the strengths of each family member.

2. The Competing Claims of Biological and Foster Parents

After accepting the care of children through voluntary placements or protective custody hearings, child welfare agencies delegate physical custody and decisions on routine childcare to foster parents. However, with more difficult decisions about education, medical care, and discipline, the agency, the biological parents, and foster parents may have competing claims.

The best approach may depend on specific circumstances. Parents who are hospitalized or unable to care for their children because of serious illness have strong claims to make important decisions on behalf of their children following placement. In abuse and neglect situations, however, it is generally appropriate for decisionmaking to be left with the child welfare agency. Moreover, the reality for some foster parents is an overwhelmed and slow-to-act agency, an absent or uninterested biological parent, and a close emotional tie to the foster child, especially for those who hope to eventually adopt the child. Although there is a strong case for supporting the interests of biological parents, the bond that develops in many foster families should also be considered. Continued dialogue is essential among advocates of biological and foster parents, child welfare agency officials, social workers, and attorneys to forge greater consensus on decisionmaking roles.

3. Advocating Categorical Funding or Child Welfare Reform

Throughout the HIV epidemic, advocates have struggled with the conflict between supporting categorical programs for people with HIV or meeting service needs and changing policy through the disability movement and other efforts that promote systemic reform. With some notable exceptions, such as vigorous advocacy for the federal Americans With Disabilities Act, the HIV community generally supported the categorical approach, as reflected by funding measures including the Ryan White CARE Act. A similar challenge faces those advocating for children and youth surviving parents with AIDS: Should their needs be addressed through categorical programs and funding or through reform of systems that affect families, such as child welfare, education, judiciary, and health care?

Advocates and policymakers for children and families should push for both approaches. Reforming the overextended child welfare system is vital to assisting all children in need. In the long run, only broad-based reform will meet the challenge for HIV-affected families and for all families at risk. In 1991, the Child Welfare League of America issued a "blueprint" for child welfare policy directed at federal legislators, program administrators, child welfare agencies, foster parents, and social workers.[3] At the same time, the needs of surviving children and their caretakers cannot wait for systemic reform. Support is needed now for targeted programs to assist HIV-affected families, such as transitional programs that commence after the death of the biological parent and special subsidies for low-income legal guardians.

CONCLUSION

In commenting on the study that first presented the epidemiological model discussed in this report, Stephen W. Nicholas and Elaine J. Abrams, pediatricians at Harlem Hospital in New York City, said: "As with many of the successful AIDS programs established to date, such model programs [dealing with orphaned youth] very likely will need to cross traditional boundaries, improve interagency communications, and establish new collaborative relationships." The recommendations contained in this report will require all these — and more.

Drs. Nicholas and Abrams called youngsters who survive the death of a parent from AIDS the "silent legacy" of the disease.[4] This report is an attempt to give voice to their often unspoken sorrows and their urgent needs as well as to propose solutions for the problems facing their families and caregivers. The children, however, can speak more eloquently for themselves than we can for them. Listen to "Marie," whose mother and sister are HIV-infected.

> Sometimes I worry a lot...I don't want any part of my family to die. If they did I would cry a lot. If I had one wish I would wish them to be back alive again. I guess if I had to I would learn to live without them. But I would never stop missing them.[5]

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APPENDIX

AIDS and Orphans: Unmet Needs in Six Cities
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The Orphan Project

The Orphan Project is a research study designed to explore policy options to meet the needs of the entire spectrum of affected children - from dying infants to healthy adolescents and young adults. There is no single solution, and each option has advantages and disadvantages. Moreover, there are different potential roles for the public and private sectors. Of particular concern are issues around confidentiality and disclosure, custody and placement, benefits program, and bereavement. Although New York City is its primary focus, the Project is also collaborating with concerned individuals and organizations in other regions.

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THE ORPHAN PROJECT

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